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نموذج رقم (١٦)
اقرار والتزام بالمعايير الأخلاقية والأمانة العلمية وقوانين الجامعة الأردنية وأنظمتها وتعليماتها لطلبة الدكتوراة

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عنوان الاطروحة: Stressors and ways of Coping Among Jordanian Patients Undergoing Hemodialysis

اعلن بأنني قد التزمت بقوانين الجامعة الأردنية وأنظمتها وتعليماتها وقراراتها السارية المفعول المتعلقة باعداد اطروحات الدكتوراه عندما قمت شخصيا" باعداد اطروحتي وذلك بما ينسجم مع الأمانة العلمية وكافة المعايير الأخلاقية المتعارف عليها في كتابة الأطروحات العلمية. كما أنني أعلن بأن اطروحتي هذه غير منقولة أو مستلة من أطاريح أو كتب أو أبحاث أو أي منشورات علمية تم نشرها أو تخزينها في أي وسيلة اعلامية، وتأسيسا" على ما تقدم فانني أتحمل المسؤولية بأنواعها كافة فيما لو تبين غير ذلك بما فيه حق مجلس العمداء في الجامعة الأردنية بالغاء قرار منحي الدرجة العلمية التي حصلت عليها وسحب شهادة التخرج مني بعد صدورها دون أن يكون لي أي حق في التظلم أو الاعتراض أو الطعن بأي صورة كانت في القرار الصادر عن مجلس العمداء بهذا الصدد.

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STRESSORS AND WAYS OF COPING AMONG JORDANIAN PATIENTS UNDERGOING HEMODIALYSIS

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COMMITTEE DECISION

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Dedication

This dissertation is dedicated to the loving memory of my father. I will not forget your unconditional love and support through my educational endeavor and I treasure the time we shared. To my mother who is always giving me so much love and support and who always encourages me towards more success. To my family and friends who have been a great motivation and inspiration to carry on with graduate education, and who make my life beautiful.

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Table of Contents

List of Figures

List of Tables

List of Appendices

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ABSTRACT

Background:
End-Stage Renal Disease (ESRD) is irreversible and life-threatening condition. In Jordan, the number of ESRD patients treated with hemodialysis is on the rise. Hemodialysis is associated with number stressors. Identifying stressors and coping strategies used may help nurses to gain a clearer understanding of the condition of these patients and thus institute effective care planning.

Aim:
The purpose of this study was to identify stressors perceived by Jordanian patients on hemodialysis, and the coping strategies used. Participants' characteristics were tested for correlations with the stressors and coping strategies. The study also attempted to explore the lived experience of these patients in regard to stressors both physiological and psychosocial and the coping strategies used.

Methods:

Mixed methods design was applied. For the quantitative study, a convenience sample of 131 Jordanian men and women was recruited from four out patients 'dialysis units in four hospitals in the city of Amman (Two units from government sector, one from private, and one unit from a teaching hospital. Stressors perceived by participants on hemodialysis and the coping strategies used were measured using Hemodialysis Stressor Scale, and Ways of Coping Scale- "Revised". Participants filled a demographic data questionnaire. Means, frequencies, and standard deviations were computed, and appropriate measures of association between variables were used. For the qualitative study, the lived experience of four male and five female participants was explored using Phenomenological approach.

Results:
Findings showed that patients with ESRD psychosocial stressors scores mean was higher (2.56), than the mean of physiological stressors (2.26). Positive reappraisal

coping strategy had the highest mean (1.91) among the coping strategies and the lowest mean was accepting responsibility (1.13). The results were supported by themes that emerged from the qualitative study e.g. time wasted on dialysis days affects daily living, and spiritual beliefs play a major role in coping.

Conclusion: Attention should be focused towards the psychosocial stressors of patients on hemodialysis and also helping patients utilize the coping strategies that help to alleviate the stressors. The most used coping strategy was positive reappraisal strategy which includes faith and prayer.

Key Words: Hemodialysis, Stressors, Coping.

CHAPTER 1

INTRODUCTION

End Stage Renal Disease (ESRD) is a growing health problem in Jordan which imposes major stress on those afflicted (El-Lozi & Ahmad, 1994). Diabetes mellitus and hypertension are the leading causes of ESRD requiring hemodialysis in Jordan (Abdullah, Ahmad, Batieha, & Ajlouni, 2007). In Jordan, ESRD has been growing rapidly in recent years. The population in the 2004 census was 5.29 million with a growth rate of 2.5% (Department of Statistics, 2004). With a calculated population over 6.88 million in 2009, over 3182 individuals are receiving hemodialysis, giving a prevalence rate of 462 per million, (National Kidney Diseases Registry, 2009). These statistics include patients from the Ministry of Health (MOH), the private sector, the Royal Medical Services dialysis units, and patients at the University of Jordan Hospital. This prevalence is expected to rise by the end of 2010.

Chronic kidney disease is the gradual loss of the renal function over a period of a year or more (Mitch, 2007; Swan & Keane, 2001). When kidneys fail to carry out their function, they are no longer able to concentrate urine, maintain electrolyte balance or remove waste from circulation (Tolkoff-Rubin, 2007; Mitch, 2007; Swan & Keane, 2001). Chronic kidney disease patients develop high blood pressure, an excess of body fluids, bone disease and anemia due to a reduced production of red blood cells. When kidney function decreases to less than 15% of its original function, CKD is then called stage V or ESRD, and it therefore becomes life threatening if not treated (Johnson et al., 2004). Mitch (2007) indicated that CKD is usually diagnosed by screening a category of people known to be susceptible to kidney problems, such as those who have diabetes, high blood pressure, and those with other kidney-related diseases. End Stage Renal

Disease can likewise be diagnosed, when it causes symptoms complications like cardiovascular disease or anemia. End Stage Renal Disease is best treated with hemodialysis. Hemodialysis is a life sustaining medical treatment for this type of chronic disease (Khanna & Krediet, 2009; Kallenbach, Gutch, Stoner, & Corea, 2005; Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001). The chronic disease and process of hemodialysis treatment are long-term stressors that alter patients' well being and everyday life style (Herlin & Wann-Hansson, 2010; Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2004.

The aim of this study was to examine and explore the physiological and psychosocial stressors of Jordanian patients on hemodialysis and the used coping strategies. Mixed methods design was used to achieve the aim of the study. This chapter presents a statement of the problem for this dissertation, a brief description of Chronic Kidney Disease (CKD), terminology used, treatment modalities, physiological and psychosocial stressors, and coping strategies used by participants on hemodialysis. This chapter will also show the significance of the study to nursing, the proposed theoretical model used for the purpose of this study, and the conceptual and operational definitions used in this study.

Statement of the Problem

Patients with ESRD face many changes in their lives with the initiation of routine hemodialysis treatments (Bapat, Kedlaya, & Gokulnath 2009; Polaschek, 2003). Different from other chronic illnesses, the life line of participants on hemodialysis remains to be their dependence on the hemodialysis machine, which is associated with many physiological and psychosocial challenges (Al Eissa et al., 2010; Hagren et al., 2004; Molzahn, Bruce, & Sheilds, 2008).

The chronicity of the ESRD and hemodialysis treatment imposes many physiological as well psychosocial stressors on patients. In order to effectively assist Jordanian patients on hemodialysis to live with this chronic disease and treatment modality, the role of nurses is to understand the challenges of the hemodialysis experience as well as the coping strategies used from the individual's perspective. Without evidence based practice to examine and explore the stressors Jordanian patients on hemodialysis face, the nurses and other health team members have no clear understanding of these stressors and how patients on hemodialysis cope with them.

Studies that addressed the importance of understanding hemodialysis stressors and coping among the Jordanian patients on hemodialysis are seldom. El-Lozi and Ahmad (1994) had studied hemodialysis stressors among Jordanian patients on hemodialysis by using some items from Hemodialysis Stressors Scale as well as adding some items added by the authors without addressing the coping strategies among patients on hemodialysis. At the moment there are no guidelines or policies that help nurses in the assessment of the stressors or coping strategies used by Jordanian patients on hemodialysis.

Renal replacement therapy.

Since the kidneys are not functioning sufficiently, patients with ESRD have three choices of therapy: Hemodialysis, peritoneal dialysis, or renal transplantation (Tolkoff-Rubin, 2007; Mitch, 2007). Of the two forms of dialysis, hemodialysis is mostly used. Hemodialysis is a blood purification technique whereby toxic metabolic substances are separated and removed from the patients' blood through a semi-permeable membrane into a dialysis solution. Hemodialysis treatments require two, or usually, three sessions a week and each session lasts three to five hours (Locatelli et al., 2005).

Stress and Stressors.

Patients with ESRD undergoing hemodialysis face various types of stressors related to the treatment (Welch & Austin, 2001; Polaschek, 2003; Yeh & Chou, 2007). Stressors are external and internal pressures, events or stimuli on an individual that cause stress (Stuart, 2009).

Hemodialysis is a lifelong treatment in which patients are faced with many physiological and psychological demands that are considered stressful (Mok & Tam, 2001; Kaba et al., 2007; Molzahn et al., 2008; Cinar, Barlas, & Alpar, 2009; Al Eissa et al., 2010). Physiological stressors that impose limitations create stress and alter daily life, this includes; fluid and diet restrictions, reduced mobility, medications, fatigue, complications associated with therapy, vascular access surgeries and length of treatment (Bezerra & Santos, 2008; Welch & Austin, 1999; Welch & Austin, 2001). Aadditionally, the pathological effects of ESRD include fluid retention, anemia, elevated blood pressure, renal osteodystrophy, accelerated cardiovascular disease and sexual dysfunction (Mitch, 2007).

Psychosocial disruptions are also common problems among individuals with ESRD (Cukor et al., 2007; Welch & Austin, 2001; Kaba et al., 2007; Jablonski, 2007). There are multidimensional psychosocial problems facing ESRD patients that include fatigue, anger, fear, depression, anxiety, family and social isolation, poor adherence to treatment, work problems, and more (Cukor et al., 2007; Yeh & Chou, 2007).

According to Welch and Austin (2001), individuals with ESRD on hemodialysis experience stressors that include but are not limited to dependency on dialysis staff, length of treatment, itching, vomiting, and difficulties in obtaining transportation to and from the dialysis unit. As a result, the long standing effects of the dialysis stressors mentioned include; a lack of social performance and diminished psychosocial health

(Cukor, Cohen; Peterson, & Kimmel, 2007; Morsch, Goncalves; & Barros, 2006; Kumar, Amalraj, Soundarajah, & Abraham, 2003). The stressors in the lifestyle of individuals with ESRD on hemodialysis can cause major life changes in daily functions (Welch & Austin, 2001; Hagren et al., 2004) and it also affects the patients' professional career (Cleary & Drennan, 2004).

Coping.

To investigate strategies used to cope with hemodialysis stressors, Yeh and Chou (2007) conducted a study and concluded that the most common coping strategies among individuals with ESRD on hemodialysis are emotion-focused, avoidance, and isolated thoughts. In addition, a study exploring coping strategies was conducted by Walton (2007), which focused on how spirituality influences the lives of American Indians with ESRD on hemodialysis. Walton concluded that these individuals reported an increased connection with God, prayer, and their relationship with others which resulted in significant spiritual support systems that helped them to maintain balance and adjustment in their daily struggle with their disease.

Significance of the study

Since the incidence of patients on hemodialysis being on the rise, the nursing care for these types of patients is necessary throughout their lives. Nurses, social workers, doctors, and other health team members working with patients on hemodialysis need to understand the hemodialysis related-stressors both physiological and psychosocial, and the strategies used to cope with the stressors of the treatment. This understanding is important in order to provide patients with the care and information to assist them in alleviating these stressors and enhancing coping strategies in the hopes of assisting them to live as normal life as possible.

In Jordan, limited research has focused on the stressors and coping of patients on hemodialysis. Therefore, this study was designed to investigate hemodialysis stressors and coping strategies by applying quantitative and qualitative approaches. Thurmond (2001) indicated that incorporating the two methods strengthens the study findings, and enhances the researchers' ability to interpret the findings. Research on this subject will lay the basis for development of a theoretical model that examines the relationship between perceived hemodialysis stressors by patients on hemodialysis and the understanding of the coping strategies used.

Purpose of study

The purposes of this study are to:

1- Examine the psychosocial and physiological stressors among Jordanian patients with End Stage Renal Disease on Hemodialysis.

2- Explore the relationship between characteristics of Jordanian patients with End Stage Renal Disease on Hemodialysis, the stressors and the coping strategies used.

3- Describe the lived experience of Jordanian patients with End Stage Renal Disease on Hemodialysis.

Research questions

The following research questions were examined in the study:

1- What are the psychosocial and physiological stressors and coping strategies used among Jordanian patients with End Stage Renal Disease on Hemodialysis?

2- What are the inter-relationships among the patients' characteristics (age, gender, education level, marital status, number of house hold members, house hold income, and length of time on dialysis), with stressors and coping strategies in Jordanian patients with End Stage Renal Disease on Hemodialysis?

3-What is the lived experience of Jordanian patients with End Stage Renal Disease on Hemodialysis?

Theoretical Model

Stress and coping theory will be used as a guide for this study. Lazarus and Folkman (1984) have established a stress coping model which has been utilized to understand how individuals cope with stressors such as chronic illnesses.

Stress and Stressors

Stress, in the context of the transactional model, acknowledges the interactions between person and environment. Lazarus and Folkman has defined stress as a ‘‘particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19). Since persons and the environments reciprocally affect each other, the process is viewed as transactional whilst the person is interacting with changing events and moments in the environment. Stressful events stimulate stress. Stressors are circumstances that are appraised as stress and threaten to exceed the available resources to overcome stress (Lazarus & Folkman, 1984).

Cognitive perception of Stress.

When people encounter a stressor, they cognitively appraise the situation. Lazarus and Folkman (1984) propose that stressors are cognitively interpreted dependent on how a person perceives of stress and how much the situation is important to the person. Appraising stressors may range from no harm to harm the individual’s well-being.

The transactional theory of stress proposes that people cognitively evaluate the person-environment interaction (Lazarus & Folkman, 1984). Transactional process focuses on persons’ subjective evaluation and awareness of the existing stressors and

the impact it has on the individual's stress response. From this perspective, when stress arises individuals appraise the situation to see if it is exceeding their personal resources to handle the stress. If the stressors exist, the persons subjectively appraise their relevance to them (Lazarus, 1999).

Lazarus and Folkman (1984) introduced the term "appraisal" as a component of the stress coping theory. Stress appraisal involves the cognitive evaluation of external demands, environmental constraints, and personal recourses. Since the appraisal is an active negotiation process, it can be either purposeful and conscious or spontaneous and unconscious (Folkman & Moskowitz, 2004; Lazarus, 1999). The outcome of the cognitive appraisal of a situation often elicits an emotional response that is accompanied by a motor behavioral, and physiological response. This action is the suitable coping response to the situation (Lazarus, 1993).

The cognitive appraisal includes three types of appraisal identified as "primary appraisal", "secondary appraisal", and "reappraisal."

Lazarus and Folkman (1984) described three subdivisions of primary appraisal as irrelevant, benign-positive appraisal and stressful encounters. Irrelevant appraisals occur when the possible outcome of interaction between the person and environment has no implication on the persons' well-being. In other words, individuals have no vested interest from the interaction result. Benign-positive appraisals occur when an encounter is appraised positively and does not hold potential negative outcomes for the individual's well-being. However, what is appraised as positive can possibly become harmful later. This illustrates that the appraisal process can be complex depending on individual factors and the context of the situation. A stressful encounter is when individuals have a potentially negative result or the situation has already been injurious to the individuals' well-being. In appraising the stressful event, individual's focus on

three kinds of appraisals: harm or loss, threat, and challenge. With harm or loss appraisal, individuals have sustained a physiological or emotional loss. A threat appraisal is an anticipation of harm or loss that has not occurred. Yet the significance of the threat is that it already set the stage for anticipatory coping. Lastly, challenge appraisal refers to situations that hold the potential for mastery or gain and can also be considered as an antecedent to positive personal growth by applying coping strategies to alleviate stressors.

Secondary Appraisal is evaluation of “which coping options are available, the likelihood that a given coping option will accomplish what it is supposed to, and the likelihood that one can apply and articulate a strategy or a set of strategies effectively” (Lazarus & Folkman, 1984, p. 35). Finally, “Reappraisal” is a further evaluation of the situation. Reappraisal is influenced by an individual’s attempt to cope with the situation and from the continuous evaluation of the interaction between the person and the environment. The perception of the stressors influences the way a person emotionally responds to stressors which suggests that appraisal acts as a mediator between stressors and coping strategies (Lazarus, 1993).

Antecedents of stress appraisal.

Antecedents are situations that result in the development of appraisal and coping strategies. Lazarus (1991) defines antecedents as “personal resources, such as wealth, social networks, competencies, commitments or beliefs, on one hand, and objective demands, critical events, or situational constraints on the other” (Schwarzer & Taubert , 2002, p. 3). According to this definition, antecedent variables are personal factors (goals, belief systems); and environmental factors (demands, constraints, resources, ambiguity, and imminence).

Defining Coping.

Folkman and Lazarus (1980) stated that a "comprehensive definition of coping needs to include both emotion regulating and problem-solving functions" (p. 221). According to the stress coping theory, each individual employs a wide range of cognitive and behavioral coping strategies in a specific stressful situation based on the individual's appraisal of the situation; this determines which coping strategies are used. In addition, Lazarus and Folkman (1984) listed some factors that affect the use of the stress coping strategies. These factors include: age, gender, history, genetics and existence of other diseases.

The aim of coping is to either modify the problem (problem-focused coping) or reduce the emotional discomfort (emotion-focused coping). Active coping, planning, and suppression of competitive activities are examples of problem-focused coping that aim to alter the external individual environment relation that caused the stress (Lazarus & Folkman, 1984). Wishful thinking, avoidance, positive re-evaluation, idealism, community support are examples of emotion-focused coping which aim to regulate emotional reaction.

The dominant theoretical framework of coping with chronic illnesses has been the contextual model of coping (Lazarus & Folkman, 1984). According to the model, coping is particularly impacted by the demands of the specific situation that a person is facing. When facing a stressful situation, the individual "evaluates the significance of what is happening for his or her well-being" (Lazarus & Folkman, 1984, p. 52-53). In view of that, the term coping refers to the cognitive and behavioral activities which an individual uses in an attempt to manage a stressful situation.

Strategies of coping.

Research in adaptation had proposed that successful coping with stressful situations necessitated that an individual's coping response will be suitable to the demands of the situations. In situations where individuals have little or no control or are not able to manipulate the situation; avoidant or emotion-focused coping strategies may be employed in that particular situation since the individual has little personal control over the situation (Zeidner, 1994).

Problem-focused coping takes place when an individual perceives that the stressful situation is changeable; it is an attempt to manage the situation causing the stressor. An example of problem-focused coping includes defining the situation and acting to alleviate the problem. Emotional-focused activities aim to reduce or regulate the emotional distress associated with a problem. Examples of emotional-focused coping include wishful thinking, avoidance of confrontive behavior, and distancing oneself from the situation; all of these activities cognitively minimize emotional distress.

Overall, it seems that coping is a complex process that is mainly dependent on the nature of the particular stressor and how it is perceived. In addition a variety of coping strategies have been employed among individuals for the same situation (Carver & Scheier, 1994).

Folkman and Lazarus (1985) developed a coping instrument, referred to as the "Ways of Coping Questionnaire" to measure coping behaviors. The coping framework of Lazarus and Folkman (1984) has been applied to the chronic illness population in several empirical studies (Lequerica, Forschheimer, Tate, Roll, & Toussaint, 2008; Wojtasiak, 2005). The individuals who had end-stage renal disease and were on

hemodialysis can be conceptualized as facing a chronic, unpredictable and uncontrollable stressor that may tax or even exceed the individual's resources.

Lazarus and Folkman (1984) identified eight coping strategies that individuals use to challenge stress.

1- Confrontative Coping: Aggressive efforts that are used to alter a situation; the term describes the individual as using some degree of both hostile and risk-taking behavior.
2- Distancing: Detachment or disengagement strategy that is used for minimizing the significance of the situation.
3- Self-Controlling: Efforts which are used by individuals to regulate their feelings and actions.
4- Seeking Social Support: Efforts which are used for obtaining informational, tangible, and / or emotional support.
5- Accepting Responsibility: Recognition of one's role in solving a problem.
6- Escape-Avoidance: Wishful thinking and behavioral efforts which are used to avoid confronting a problem or a stressful situation.
7- Planful Problem Solving: Problem-focused efforts to alter the situation, including an analytic approach to problem solving.
8- Positive Reappraisal: A religious dimension which includes giving positive meaning to a situation by focusing on one's personal growth experience.

Those eight strategies separate into two types of coping strategies. The first coping strategy type is problem-focused solving / problem elimination or working around the stressor. The problem is then defined and alternatives are considered. Afterwards, the best strategy for that situation is the selected and finally put into action. The second coping strategy type is emotion-focused. It entails the use of mainly

cognitive processes so as to reduce the perceived suffering. In general, people try multiple strategies, utilizing problem-solving strategies in stressful situations where there is some degree of control. Emotion-focused strategies tend to be utilized in situations where people feel they have little power like when they experience a physiological health problem (Lazarus & Folkman, 1984).

The proposed theoretical model for this study constructs the relationships between participants' characteristics and hemodialysis stressors; and between participants' characteristics and the coping strategies used. Each of the participant's characteristics is expected to influence the stressors (physiological and psychosocial), as well as influencing which strategy of coping strategy will be used. The model is adapted from the Stress/coping Model by (Lazarus and Folkman 1984). Visualization of theoretical framework for this study is presented in figure (1).

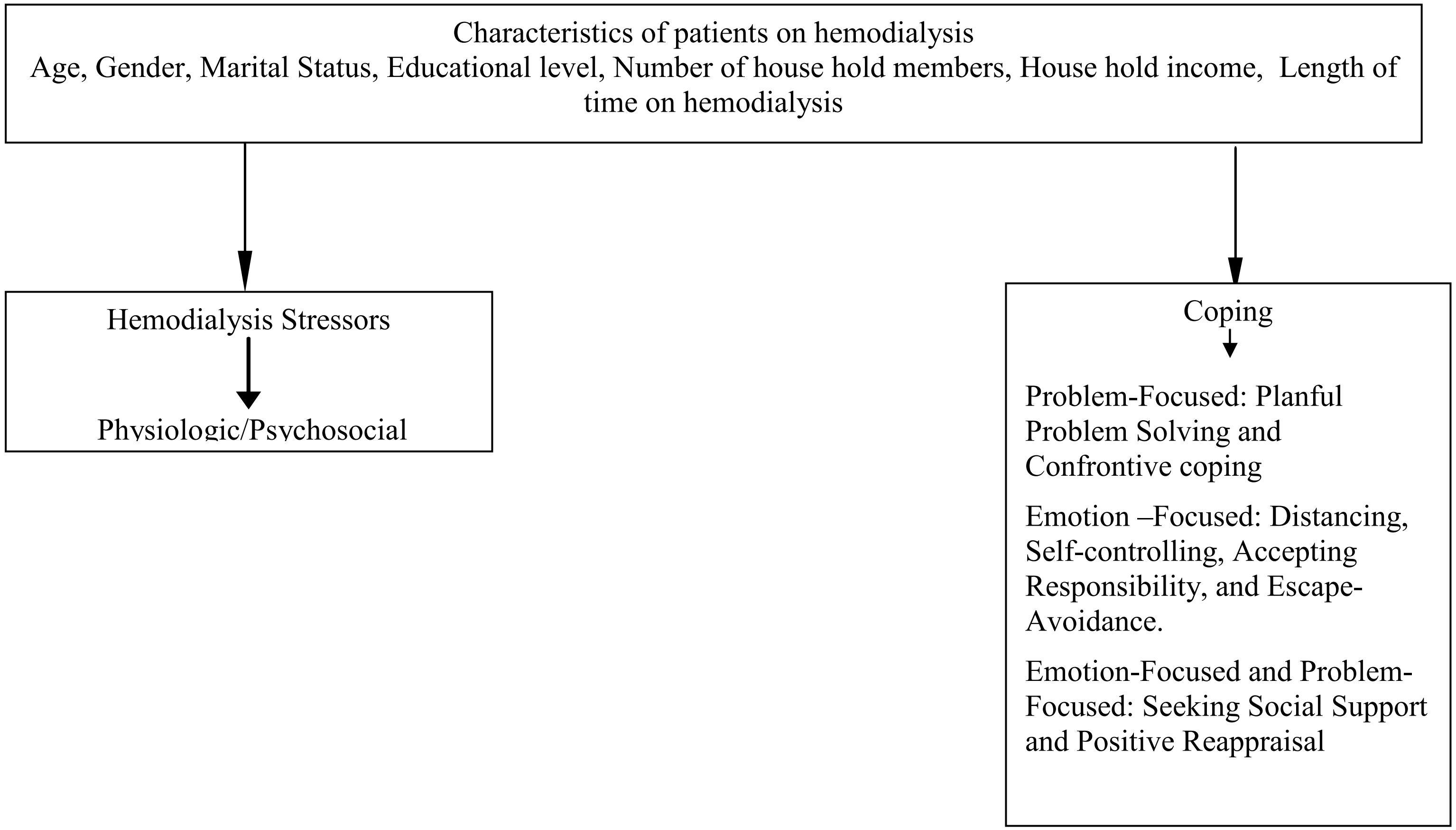


Figure (1): Model of the conceptual framework of the stress and coping with hemodialysis**.**

Conceptual and Operational definitions

Stressors.

Conceptual definition: The physiological or psychosocial stressors that elicit stress responses in individuals after they have been perceived as threatening to their well beings (Monat & Lazarus, 1991).

Operational definition: Hemodialysis Stressors Scale (HSS) is the instrument that measures physiological and psychosocial stressors perceived by hemodialysis individuals (Baldree et al., 1982) modified by Bihl et al. (1988). The scale is a self-report measure composed of 29 items; six in the physiological subscale and 23 psychosocial items in the psychosocial subscale (Baldree et al., 1982), (Appendix 3).

Coping.

Conceptual definition: Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding personal resources (Lazarus & Folkman, 1984).

Primary Appraisal***:*** Primary appraisal is the individual's evaluation of the situation as being potentially harmful to psychological well-being and is dependent on aspects of the person and the environment (Lazarus & Folkman, 1984).

Secondary Appraisal: Evaluation of "which coping options are available, the likelihood that a given coping option will accomplish what it is supposed to, and the likelihood that one can apply and articulate a strategy or a set of strategies effectively" (Lazarus & Folkman, 1984, p. 35).

Operational definition: The Ways of Coping Scale "Revised" (WOCS-R) was used to measure strategies of coping with stressful situations (Folkman & Lazarus, 1985). This scale is composed of 66 items; the 8 coping subscales are: confrontive, Planful problem solving which are considered as problem- focused strategies); escape avoidance,

distancing, accepting responsibility, and self controlling (considered as emotion-focused strategies), and positive reappraisal and seeking social support (that are considered as both problem-focused and emotion-focused strategies (Appendix 4).

Operational definition for participants 'characteristics.

Participants' characteristics: Gender, age, educational level, marital status, number of household members, household income, and length of time on dialysis in years.

Summary

End Stage Renal Disease (ESRD) is a growing health problem in Jordan which imposes major stress on the affected patients. Different treatment modalities for ESRD as well as a brief introduction about stress, stressors and coping strategies were described. The statement of the research problem, its purpose, and research questions utilized and the conceptual and operational definitions were presented. Since ESRD is a chronic illness, this study used Lazarus and Folkmans' (1984) stress/coping theory to understand how hemodialysis individuals cope with their disease and treatment.

CHAPTER 2

LITERATURE REVIEW

This chapter provides a review of the literature including a brief background of kidney function, the different treatment modalities of ESRD, treatment stressors, and coping strategies of patients with ESRD on hemodialysis. Some of the factors influencing coping with hemodialysis stressors are reviewed for the purposes of this dissertation. A concise summary of the contents concludes this literature review.

Kidneys' Function

The kidney is responsible for maintaining body's normal internal physiological and chemical balance. The Kidney has multiple functions: it balances body fluid by removing surplus fluid, electrolyte balance, elimination of waste, drugs and toxins from the blood; acid balance; production of blood cell, and helps the activation of vitamin D for healthy bones; eliminates fluid out of the body as urine. Kidneys also release hormones into the blood to control blood pressure. When kidneys are incapable of performing their normal functions, certain toxic substance, drugs, electrolyte and excess fluid which should have been excreted, are accumulated in the body. Accumulation of fluid in the body increases the potassium level in the blood which leads to cardiac arrest. The effects of accumulation of waste induce; nausea, vomiting, headaches, itching, insomnia vitamin D deficiency (Mitch, 2007).

The decline in kidney function is a serious condition. Factors that cause kidney failure consequently decrease the blood supply to the kidneys and lead to a loss in kidney functions. When kidneys completely lose their function suddenly, it is called Acute Kidney Failure (AKD). Acute Kidney Failure is often reversible, usually by the

combination of medical treatment and dialysis with complete recovery of kidney function (El Nahas & Levin, 2009; Tolkoff-Rubin, 2007). A gradual loss of kidney function over time with residual damage to the kidneys is called Chronic Renal Failure (CRF). Chronic kidney disease may be caused by diabetes, high blood pressure and other disorders. Patients are at risk from other diseases during this period such as heart attacks, and strokes. Total or nearly total permanent kidney failure is called End Stage Renal Disease (ESRD) and patients have to undertake dialysis or transplant to maintain their health and life (El Nahas & Levin, 2009; Swan & Keane, 2001). The cause of kidney disease could be primary due to disease in the kidney, or secondary systemic disease such as diabetes and hypertension. The main causes of kidney failure are diabetes; hypertension and other conditions like glomerulonephritis, inherited disease such as polycystic kidney disease, autoimmune disease; and long standing large kidney stones. Other causes include Non-steroidal anti-inflammatory drugs and pain killers, disruption of blood flow to the kidney, damage to the structures of the kidney, and block in the passage of urine out of the body (Mitch, 2007; Tolkoff-Rubin, 2007)

Treatment of ESRD.

Hemodialysis.

Hemodialysis is a method for eliminating wastes from a human's blood. If the patient has got the kidney disease of renal failure, accumulating wastes such as potassium, urea, and free water in the patient's blood must regularly be cleared. Hemodialysis is one among three renal replacement therapies; the other two therapies are peritoneal dialysis and renal transplant (Daugirdas, Blake, & Ing, 2006).

The main method of hemodialysis is the same as other methods of dialysis. Hemodialysis requires the diffusion of two solutes across a semi-permeable membrane. In hemodialysis process, a patient's blood is fed into a dialyzer which contains two fluid

chambers made as groups of capillary tubes or as parallel sheets of semi-permeable membranes (Daugirdas et al., 2006).

In the dialyzer, the human blood in the first chamber is being forced along one side of the semi-permeable membrane while a crystalloid solution of dialysate is simultaneously being forced along the other side in the other separate chamber in the opposite direction. Therefore, hemodialysis uses a counter-current flow in which a dialysate flows in the opposite direction to the patient's blood flow in the circuit. The counter-current flow sustains the focus of gradient across the membrane at a maximum and increases the efficiency of the dialysis (Daugirdas et al., 2006).

Fluid elimination is carried out by changing the hydrostatic pressure of the dialysate chamber, thereby causing the free water and some other dissolved solutes to cross over the membrane along a pressure gradient. Hence, the concentration gradients of solute between blood and dialysate will lead to wanted changes in the patient's blood solutes. Such wanted changes include: A reduction in urea nitrogen, an increase in sodium bicarbonate, and an equilibration of sodium, calcium, potassium, and magnesium (Kallenbach et al., 2005). The dialysate chamber will be under negative pressure in relation to the blood chamber so that filtration of dialysate into the bloodstream may be prevented and so that the excess blood fluid from the patient may be removed. The used solution is a highly sterilized solution of mineral ions. Wastes like urea, potassium, and phosphate are eventually diffused into the dialysis solution. Nevertheless, the concentrations of sodium and chloride will be similar to those of normal blood plasma in order to preclude their loss. Likewise, sodium bicarbonate is often added at a higher concentration than that in the plasma to make the blood acidity right, and a little amount of glucose is customarily used (Kallenbach et al., 2005).

The patient is routinely given anti-coagulating drugs during the hemodialysis process in order that blood may be precluded from clotting inside the dialysis machine. In the long-term, the hemodialysis process aims at optimizing the patients' functional status and comfort, precluding uremia and its complications, and improving survival. After the process is completed, the dialyzed blood is re-infused into the patient (Kallenbach et al., 2005).

Peritoneal dialysis with its three types, continuous ambulatory peritoneal dialysis (CAPD), continuous cyclic peritoneal dialysis (CCPD), and Intermittent peritoneal dialysis (IPD), is another option for renal replacement therapy. Once surgery is carried out, the patient will undergo a peritoneal equilibration test in which the patient's dialysate is tested and evaluated against the serum so as to determine solute clearance rates. This procedure indicates the patient's peritoneal transport rates, required dose of dialysis, and best technique (Khanna & Krediet, 2009; Kallenbach et al., 2005). The peritoneal dialysis removes waste products and fluids from the blood by using the lining of the abdominal cavity or peritoneal membrane as a natural filter. The waste products and fluids are moved from the blood vessels in the peritoneal membrane into a solution which is placed in the abdominal cavity. Peritoneal dialysis is an on-going therapy; in other words, it is intended to work all day long and on each and every day (Khanna & Krediet, 2009; Kallenbach et al., 2005).

The third modality for the treatment of ESRD is kidney transplantation, which means the surgical replacement of the failed kidney in the patient with a well functioning one from another person called a donor. Kidney transplant is an ongoing treatment which requires the receiver to take immunosuppressant medication and follow up with nephrologists (McKay & Steinberg, 2010). The Transplant recipients achieve levels of activities and health better than dialysis patients' especially physiological and

psychological domains (Bittencourt, Filho, Mazzali, & Santos, 2004). While transplant is the best option for patients with ESRD, organ donation availability remains the limiting factor (McKay & Steinberg, 2010).

In summary, End Stage Renal Disease is the loss of 95% of kidney function. Several conditions are associated with the cause of ESRD such as: hypertension, diabetes mellitus, congenital anomalies, chronic pyelonephritis, and poly-cystic kidney disease. The available treatment modalities to ESRD are hemodialysis, peritoneal dialysis and kidney transplant. Hemodialysis treatment is the most used modality.

Common Stressors for Patients on Hemodialysis

Hemodialysis is the most common treatment modality for ESRD which also has been characterized as a source of stressors. Leung (2003) conducted a study on ESRD patients on hemodialysis and concluded that from the time patients are diagnosed with chronic renal failure and eventually referred to hemodialysis as the most common option of treatment, patients were exhibiting psychosocial and physiological symptoms that affect their daily lives.

Harwood, Locking-Cusolito, Spittal, Wilson, and White (2005) explored specific stressors, which patients experienced as they approached hemodialysis. Eleven participants were interviewed and the central theme of stressors fell in three categories: Physiological stressors; psychosocial stressors; and logistical stressors. Emotional reaction was the common response all participants shared due to diet control, blood pressure control, and other restrictions that accompanied hemodialysis.

The Well-being of patients on hemodialysis is the basis of engagement in daily activities and participating in social events. Blake and O'Meara (2004) investigated physiological performance deficits among dialysis patients in comparison with a healthy matched sedentary control group. Blake and O'Mearas' study showed significant

deficits in physiological function, and neuromuscular impairments among participants on hemodialysis. Curtin, Bultman, Thomas-Hawkins, Walters, and Tschatell (2002) undertook a prospective study of 307 patients from 14 dialysis facilities to assess symptom experiences in relation to physiological and mental functioning. The common symptoms of patients on hemodialysis were clustered into three indices: (a) Fatigue/sleep (b) sexual concerns index, (c) mobility index. Physiological functioning was associated with experiencing a cluster of fatigue-related symptoms, a cluster of mobility-related symptoms, and the symptom of itchy skin. This suggested patients' ability to perform routine activities in their daily lives was compromised due to the physiological stressors they face.

Daily routine is often influenced by hemodialysis. Bezerra and Santos (2008) assessed the perception of patients undergoing hemodialysis daily activities regarding their occupational functioning. The Participants were 70 Brazilians on hemodialysis. Self- Assessment of Occupational Functioning was used. It was concluded that patients on hemodialysis were not totally incapable of performing their daily tasks. However, Bapat et al. (2009) explored illness disturbance among Indian patients on hemodialysis and the association between illness disturbance and patients demographic. Bapat et al. concluded illness disturbance demonstrated in their daily life to various areas of health, work, finance, and found an association between illness disturbance and occupation.

Baldree et al. (1982) developed a dialysis specific measurement tool for identifying stressors and the level of stress. The fluid restriction was the major stressor reported. The psychosocial stressors were greater than that of physiological stressors. The top physiological stressor was muscle cramps followed by fatigue, whilst patients who had been on dialysis longer than 13 months reported more stressors than those with

less than 12 months treatment. This was consistent with Lok (1996) finding that the elevation of stressors was related to longer dialysis duration.

In a recent hermeneutical phenomenological study to explore the experiences of 16 ESRD patients, it was found that therapy attendance is time consuming (Moran, Scott, & Darbyshire, 2009). The experience of waiting was boring for the patients and two main themes emerged “killing time” and “wasting time.” Patients who experienced killing time were connected physically to hemodialysis machines and described their waiting experience as full of boredom, watching the clock while waiting impatiently for the treatment to end. The second theme “wasting time reflects the waiting time patients experienced which was unnecessary prior and post treatment without engaging in everyday activities’’.

Another qualitative study by Hagren et al. (2004) interviewed 41 patients of ages 29 to 86, with a minimum of three months on hemodialysis, and a content analysis was used to identify common themes on how illness and treatment encroached upon time. The theme “not finding space for living” was about the intrusiveness of treatment in regards to their daily life while struggling with time consuming treatment, life was restricted. They also felt vulnerable in the care situation. They expressed the need for caregiver attention and of what the participants felt about hemodialysis treatment.

There were other studies that explored what it is like to live on hemodialysis. Herlin and Wann-Hansson (2010) conducted a qualitative study on nine patients aged 30 to 45 years with a minimum of six months on hemodialysis, to gain insight into the patients’ experiences. A phenomenological approach was used; face-to- face interviews lasting 45 to 90 minutes were taped and recorded. The data were transcribed and analyzed. “Lack of freedom” was the essential meaning of the phenomenon and the emerging themes were “dependency on caregivers”, and “time lost in dialysis.” The

themes describe that dependency on hemodialysis was time consuming for the participants on hemodialysis as they are not experiencing normal daily life while occupied by routine of the treatment. However, participants experienced good relationships with their caregivers.

Welch and Austin (1999) conducted a study on 86 patients using hemodialysis stressors scale. The study was designed to see if time altered the perception of treatment-related stressors. The HSS was administered twice, three months apart. The highest ranked stressor in both interviews was life style changes. The second highest stressors were fatigue, feeling sick, and an inability to travel freely, and the third was related to vascular access problems. However, older patients suffered from physiological stress more than younger patients. Bihl et al. (1988) had identified stressors imposed on dialysis patients such as failing vascular access, transportation difficulties, and boredom during dialysis sessions. More recent studies found those physiological symptoms such as fatigue; itching, cramp; sleep disturbance, tiredness, and length of treatment, play a major part in the psychosocial stress associated with treatment (Lok, 1996; Mok & Tam, 2001).

Modalities of dialysis treatment also affect stressors and coping strategies. Kumar et al. (2003) conducted a cross sectional study which included 50 patients. The aim of this study was to explore the level of stress and coping ability among continuous ambulatory peritoneal dialysis (CAPD) and patients on hemodialysis. Data were collected from the patients using Stress and Jalowiec Coping Scale (JCS) questionnaires. A stress scale was developed from literature and JCS modified to suit the family background and the socio-economic Indian population. Stress levels among CAPD patients were significantly lower at all aspects of physiological, psychological, socio-economic, and overall stress. Additionally, the overall coping ability score among

CAPD patients was significantly higher as compared to patients on hemodialysis (p<.001). Patients receiving CAPD were enjoying vocational, social, recreational activities and activities of daily living, much better than patients on hemodialysis which all may be all be adversely affected by hemodialysis regimen treatment unlike CAPD therapy. Kumar et al. (2003) concluded that CAPD modality was less stressful and patients coped better with life stressors.

Common Coping Strategies among Patients on Hemodialysis

Lazarus and Folkman (1984) defined Coping strategies as cognitive and behavioral efforts utilized by individuals to control, reduce, and tolerate stressors. Additionally, Lazarus and Folkman categorized coping strategies into problem-focused and emotion-focused strategies. Problem-focused strategies help manage or alter the person or environment causing the distress. Emotion-focused strategies involve regulating emotions and feelings and utilizing techniques such as distancing, self-control, escape-avoidance, and accepting responsibility (Lazarus & Folkman). Higgins and Endler (1995) classified coping strategies into three main classes: Task-oriented coping, which involves task actions effort to reduce stress. Emotion-oriented confronting and dealing with stress, which is directed towards altering the emotional response to stressors that is no longer inducing negative emotional responses. The final third strategy is avoidance-oriented coping, distraction and social diversion such as losing hope, avoiding situation, and denying an existence of a problem. Takaki et al. (2005) studied the relationship between coping with stress and employment in patients on hemodialysis. The goal of the study was to examine the relationship between emotion and task oriented coping with stress and employment among 317 participants undergoing hemodialysis in Japan. Participants completed questionnaires which articulated their stress perceptions. They concluded that emotion oriented coping was

associated with employment in both genders. On the contrary, task oriented coping was not associated in both genders. Physiological function presented a positive association with occupation for men; and gastrointestinal diseases have a positive association with occupations in women.

Logan, Pelletier-Hibbert, and Hodgins (2006) conducted a correlational study between HSS and JCS, to investigate the coping strategies among hospitalized Canadian patients on hemodialysis over 65 years and old age. The JCS was developed based on Lazarus and Folkmans' coping theory of stress and coping, and is designed to measure coping behavior across a wide range of physiological, emotional, and social stressors (Strickland & Dilorio, 2003). The highest ranked stressors were identified as limits in time and place for vacation. The second was feeling tired and the third was a decrease in social life. Restriction of fluids ranked the fourth on HSS.

The common coping strategies on JCS were optimism, supporting mechanisms; including prayer and trust in God, and palliative. A negative relationship was found between age and reports of coping strategies, indicating that older participants use fewer coping strategies. The length of time on hemodialysis did not affect the participants' appraisal of stressors. In contrast to Mok and Tam (2001) who used HSS and JCS and found fluid restriction was the highest ranked stressor followed by food limitation, itching, fatigue and cost. The common coping strategy was to accept the situation because very little can be done, the second telling oneself not to worry because everything will work out, and the third highest was telling oneself that this problem was really not that important. The dialysis time affects the coping parameters. The mean score for psychological stressors was greater than it was for physiological stressors; and participants over 55 years of age had more physiological stressors than those less than 55 year old.

Yeh and Chou (2007) investigated stress and the relation between stress and the coping strategies among 2642 Taiwanese participants on hemodialysis. The Hemodialysis Stressor Scale revealed that of the seven subscales, daily activities was the highest perceived stress, followed by physiological symptoms, dependency on medical staff, and the fourth rank was food and fluid restrictions. The common coping strategies among this group receiving hemodialysis were: Emotion oriented, support seeking, avoidance, and isolation of thoughts. The top four hemodialysis stressors daily activity, physiological symptoms, dependency on medical staff and food and fluid restriction were each positively correlated with emotion-oriented, avoidance-oriented and isolation thoughts. In addition physiological symptoms and dependency on medical staff were positively correlated with support seeking coping.

Several researchers have found conflicting results regarding how age affects coping strategies and their effectiveness. Folkman, Lazarus, Pimley and Novacek (1987) found that older people when faced with stressful situations rely on cognitive approaches and avoidance coping. Folkman and her colleagues reported that older people proportionately use more emotion-focused coping such as distancing, acceptance of responsibility, and positive reappraisal compared to younger people. However, Melanson and Downe-Wamboldt (2003) indicated that when coping with chronic illness, older persons tended to use confrontative coping. From another point of view, Quayhagan and Quayhagan (1982) found that older adults were more likely to use emotion venting and less likely to seek help, mobilize social support resources, or problem solve.

Lindqvist, Carlsson, and Sjoden (2000) examined the coping strategies' of 1200 Swedish patients on dialysis using JCS. The study found that the three commonly used coping styles were: the confrontative, the optimistic and the self-reliant in the general

sample group. However, young and middle-aged groups used confrontative and emotive styles more than the elderly 60 year old and above group did.

Furthermore, men and women engage in different coping strategies. Tamres, Janicki, and Helgeson (2002) pointed out that men and women respond differently to cope with stressors. A number of old studies (Pearlin & Schooler, 1978; Stone & Neale; 1984) suggested that men are more apt to respond directly to the stressors and utilize problem focused coping. Women, however, in the Tamres et al. (2002) study were more likely to engage in problem focused strategies, and utilize active coping and hence use social support. Of the emotion-focused coping strategy, women are more likely to seek social support for emotional reasons. Additionally, men use more avoidant coping strategies for relationships and other health problems. O'Neill and Morrow (2001) indicated that positive social support has a protective effect for both women and men while interpersonal conflict and dissention have a negative effect.

El-Lozi and Ahmad (1994) studied stressors reported by Jordanian patients and gender perception of hemodialysis stressors among 43 female and 47 male patients. Mean age of the participants was 42 years range of 18 to 62 years. Sixty-one of the participants were married, 27 participants were not married and two widowed. El-Lozi and Ahmad had used Hemodialysis Stress Scale which consisted of 30 items. Twenty-three items were developed from literature and six items were coined locally by the staff working with patients on hemodialysis. A rating scale was developed to measure the incidence and severity of physiologic, psychological, and social stressors associated with hemodialysis treatment as perceived by patients. The study had revealed that female patients suffered from psychological stress more than male patients suggesting that women are more sensitive to stress than men. However, when comparing the severity of the three subscales, social and psychological stressors were more sever

reflecting the impact of psychosocial problems as source of hemodialysis stressors. Lok (1996) examined the stressors of 58 Australian dialysis patients and compared the relations between stressors and coping. The findings showed that limitations on physiological activity were the highest ranking stressor, followed by decrease in social life; the coping pattern was problem-focused. Lindqvist et al. (2000) found that Swedish origin ethnicity was the least to use emotionally-oriented coping styles than the non-Swedish origin. Mok and Tam's (2001) identified fluid and food restrictions as the highest stressors to the Chinese. Mok and Tam gave an explanation of the social and cultural beliefs within the Chinese families, friends and culture indicating that sipping Chinese tea is an important social interaction within families and friends. Moreover, a common cultural belief that soup speeds up healing. Yeh and Chou (2007) studied stressors in 2642 Taiwanese patients. Yeh and Chou found physiological symptoms, dependency on medical staff, and vascular access problems rated highest as stressors. The coping strategies' were emotion focused, support seeking, avoidance, and isolation thoughts. This indicates treatment orientated stress is different to the culturally similar group sample found in Mok and Tam's study.

Spinale et al. (2008) estimated the linkage among spirituality, social support, and survival in 166 ESRD on patients on hemodialysis. The participating patients filled out a questionnaire on the psychosocial variables, quality of life, and religious and spiritual beliefs. Their social support was also associated with spirituality, religion, and religious involvement measures. The study's data hinted at a clear association between spirituality and survival because of the increase in social support.

For the qualitative part in this mixed methods study, the phenomenological approach was utilized. Phenomenology is one of many types of qualitative research that describe accurately a participant's "life world" and understand their meanings in

relation to what is being studied based on their "lived experiences" (Speziale & Carpenter, 2007). Phenomenology, as a philosophical research tradition, was developed by Edmund Husserl (1859-1938) and Heidegger (1889-1976). Both are philosophers and considered phenomenologist, but their approaches to research and understanding life experiences were different. However, there are two main approaches to phenomenological research: Descriptive phenomenology and interpretative phenomenology. Descriptive phenomenology ascribes to Husserl (1965), whose primary-interest question was “What do we know as persons?” (Koivisto, Janhonen, & Vaisanen, 2002, p. 260). Husserl's approach provides descriptions of the meaning of human experience (Koivisto et al., 2002). In contrast with Husserl, Heidegger (McConnell-Henry & Chapman, 2009) moved from descriptive to interpretive approach. Heidegger argued that the researcher is part of the research; we use our experience to interpret those others (McConnell-Henry & Chapman, 2009).

Four psychologists (Van Kaam, 1966; Giorgi, 1970; Colaizzi, 1978; Van Manen, 1984) had developed three phenomenological methods that are influential in nursing research (Munhall, 2007, Marshall, Gretchen & Rossman, 2010). Similar systemic phenomenological steps were employed to conduct qualitative research starting with dividing the original descriptions into units, then the units are transformed to phenomenological meanings, and the last step is combining the transformed information to form general description (Dowling, 2007). Colaizzi had developed a phenomenological method of data analysis. The final step of Colaizzi’s systemic method is that the investigator returns to participants for validation of the investigator descriptive results with their lived experience. Colaizzi’s method suggests that the investigator's description and interpretation are acknowledged by checking the data collected with participants rather than just description by investigator. The method is

also considered as a good fit for both of Husserl's descriptive and Heideggarian's interpretive phenomenological research (Dowling, 2007).

Conclusion drawn from literature review

The reviewed literature confirms and enumerates different stressors affecting patients on hemodialysis, and explores the most used coping strategies. In the majority of the reviewed literature, psychosocial stressors appeared to be more significant for patients on hemodialysis than the physiological ones. Different coping strategies were used by patients from different cultures. The chapter presented also a brief review about the phenomenological approach that was used in this study.

CHAPTER 3

METHODS

In this study, the stressors of Jordanian patients' on hemodialysis were assessed utilizing quantitative and qualitative methods. This chapter discusses the pilot study, and the quantitative and qualitative methods employed. In addition; the study design, participant criteria, instruments utilized, and the overall guidelines of the study are described.

Mixed Methods/Triangulation

The integration of two or more research methods to investigate phenomenon is called triangulation (Casey & Murphy, 2009; Adami, 2005; Risjord, Moloney, & Dunbar, 2001). Methodological triangulation within this research study design used qualitative and quantitative approaches in order to provide a deeper understanding and a holistic description of the phenomenon. The findings from both research approaches can be relevantly applied to the improvement of nursing practice for patients who undergo hemodialysis. The literature identifies the purpose of triangulation as a method that provides confirmation and completeness of data (Casey & Murphy, 2009; Risjord et al., 2001; Thurmond, 2001). Conformability is established through the enhancement of the validity and the confidence in the findings through the use of more than one method to measure the quality. One method alone would not ensure the completeness of the data. Triangulation enables more comprehensive understanding about the hemodialysis participant's lived experiences.

Study Design

This study followed a mixed methods design; Quantitative and Qualitative designs.

1-Quantitative design

A quantitative descriptive cross-sectional correlation design was used to examine the relationships between participants' characteristics, stressors (physiological and psychosocial), and coping, among Jordanian participants on hemodialysis. In this study, no manipulation was implemented on the study variables. Thus, the purpose of this correlational research was to examine the level of psychosocial and physiological stressors among Jordanian participants with end stage renal disease treated with hemodialysis

Ethical considerations.

Prior to initiation of the study, the research proposal was reviewed and approved by the Research Committee of the Faculty of Nursing at the University of Jordan. Approval was also granted by the Graduate Faculty Board, and Ethical Committee of the University of Jordan. Other approvals were granted from administrations in three hospitals in the private sector, two hospitals from the government sector, as well as one teaching hospital. The investigator started conducting the quantitative part of the study in the four involved hospitals by herself. The unit's director introduced the investigator to the unit's staff, and then the investigator introduced herself to the potential participants. Potential participants were informed of the purpose of the study by the investigator. Risks as fatigue or tiredness from filling the questionnaires were explained. Benefits of the study such as how it may contribute to more understanding to health team members of the stressors and coping strategies of patients on hemodialysis; thus planning more effective care were presented. Potential participants were informed that

they could withdraw from the study at any time for any reason, without affecting the process of their treatment. Those who agreed to participate were requested to read and sign a consent form (Appendix 1).

Procedure.

The investigator met with the unit's director and staff at the dialysis units and explained the study and eligibility criteria of participants. The inclusion criteria of the study sample consisted of: The participant (1) had been on hemodialysis for at least six months and currently receiving hemodialysis at a minimum of two times per week (by 6 months, the routine for the hemodialysis procedure is established, and two times per week is the minimum number for dialysis sessions) ; (2) at least 18 years of age; participants of this age and above are able to understand the items in the questionnaires in order to be able to answer them; (3) able to read and write in Arabic. Participants with known cognitive impairments were excluded from the study.

Patients who were eligible for the study and agreed to participate were selected in the study sample, after a brief description of the procedure and the importance of the study were presented to them. Following that, potential participants read and signed the consent form (Appendix1). Data collection package included three paper and pen self-report questionnaires: the patients 'undergoing hemodialysis characteristics (Appendix2), the Hemodialysis Stressors Scale (Baldree et al., 1982) (Appendix 3) and Ways of Coping Scale Revised (Folkman & Lazarus, 1985) (Appendix 4). The main investigator distributed the questionnaires personally and checked complete filling of data. A pilot study was conducted.

Sampling and Setting.

A convenience sample of 131 Jordanian men and women was recruited from the city of Amman four outpatient dialysis units in four hospitals: two hospitals from the government sector, one private hospital, and one teaching hospital. These hospitals were targeted as they are four of the largest hospitals in Amman representing governmental, educational, and private health sectors.

Power analysis for a Pearson correlation was conducted in G-POWER; which is a free available program on the internet (Buchner, Erdfelder, & Faul, 1997). An alpha of 0.05, a power of 0.80, a medium effect size (p = .25), and two tails were used as a guideline (Buchner et al., 1997). The minimum required sample size was 123 participants.

Instrumentation.

Stressors perceived by participants on hemodialysis were measured by the modified Hemodialysis Stressor Scale (Bihl et al. 1988). Respondents on this HSS rated the extent of being stressed on a 4-point Likert-scale. Responses were: 1 = not at All, 2 = slightly, 3 = moderately, and 4 = a great deal. Score range for the total scale is (29 - 116), (23- 92) for the twenty three scale psychosocial items, and (6 - 24) for the six physiologic items. The higher score on the scale items indicated greater severity of stressors associated with treatment of hemodialysis as perceived by the respondents (Mok & Tam, 2001). Test re-test reliability had a coefficient of r = 0.71 with an internal consistency alpha coefficient of this scale = 0.89 (Baldree et al., 1982), indicating good internal reliability. Murphy, Powers, and Jalowiec (1985) reported reliability coefficients of 0.89 for the total stressor scale; 0.69 for the physiological subscale and .88 for the psychosocial subscale. Another source of support for scale homogeneity is the intra item correlations. Murphy et al. (1985) reported a Pearson correlation between

stressors items and total scores for 174 patients; all correlations were significant at .001. In this study, the HSS demonstrated a Cronbach alpha of (.87) for the total scale, (.84) for the psychosocial stressors subscale, and (.68) for the physiological stressors subscale The Hemodialysis Stress Scale (Appendix 3) had been translated to Arabic and back translated to English. This method is used when questions translated from the source language to the second language, and then translated back to the source of language by an independent translator (Rogelberg, 2005, p. 235).

Coping strategies used by participants on hemodialysis was measured by the Ways of Coping Scale- “Revised”: The WOCS-R was used to measure strategies of coping with stressful situations (Folkman & Lazarus, 1988). The scale had demonstrated good internal consistency reliability, and test -retest reliability and construct validity (Rexrode, Peterson, & O’Toole, 2008). The questionnaire consists of 66 statements. The response to statements is based on a 4-point Likert scale and the answers were scored as follows: “does not apply or not used” (0), “used somewhat” (1), “used quite a bit” (2), and “used a great deal” (3). The eight ways of coping subscales are confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape, avoidance, painful problem-solving, positive reappraisal (Folkman & lazarus, 1988).

The internal consistency of the WOCS-R is based upon factor analysis of the responses of 75 married couples interviewed once a month for 5 months equaling 750 observations. The alpha coefficients of the scales were .70 for confrontive coping, .61 for distancing, .70 for self-controlling, .76 for seeking social support, .66 for accepting responsibility , .72 for escape-avoidance, 66 for planful problem-solving, .79 for and positive reappraisal (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The range of the scores for the total coping scale was (0 – 198). Ranges of scores for the

subscales were (0-18) for confrontive, seeking social support; and planful problem-solving, (0-21) for self-controlling, and positive reappraisal; (0-24) for escape-avoidance, and (0-12) for accepting responsibility. In a recent study by Lequerica, et.al. (2008), Cronbach's alpha for the scales ranged from .24 to .79. Some low values of coefficient alpha for the Coping subscales may be expected when using a measure in a population different from the one for which it was developed (Lequerica et al., 2008). Cronbach alpha for the total coping scale in this study was .89, .47for confrontive coping, .69 for distancing, .42 for self-controlling,.64 for seeking social support, .55 for accepting responsibility, .68 for escape-avoidance, .616 for planful problem-solving, and .64 for positive reappraisal subscales.

The WOCS-R is already established in both the Arabic and English language. Copies of 'Ways of Coping Scale – Revised" (Folkman, 1986) in English and Arabic were obtained from the coauthor Susan Folkman at the University of California, San Francisco (Appendix 4) with permission to be used. However, the Arabic translated version of the scale was modified by an Arabic language expert to be easier to comprehend before conducting the first pilot study.

During the pilot study many participants asked about the meaning of statements they did not understand in the coping questionnaire. The questionnaire was given to six experts to be reviewed in the Arabic language to be clear for the understanding of participants. After the modifications were all agreed on, the coping scale was retyped in Arabic with the modified statements. A second pilot study was conducted on 10 different participants and there was a marked improvement in the participants' understanding of the items reflected by decreased requests for clarifications of statements' meanings. Time for filling the questionnaires was also estimated during the pilot studies which ranged between 30-40 minutes.

Participants’ characteristics: A questionnaire was created for collecting specific participants’ characteristics and related clinical information. It includes participants’ socio-demographic characteristics data that include: Age, gender (Male=1, Female=2), education level: ("Elementary / preparatory", "high school" and "above high school"), marital status (married= 1, single= 2, widowed=3), number of house hold members (living together on permanent basis), household income, and length of time on dialysis in years. Clinical information included cause of hemodialysis, other medical illnesses, duration on dialysis, and weekly days of dialysis (Appendix 2)

Data collection.

Two pilot studies were conducted. The first pilot study (*N* = 11) was conducted to gather information and investigate the applicability of the two HSS and WOCS-R to ensure clarity and feasibility of the tools, which were translated into Arabic for the main study. The purpose of the pilot study was to assess face validity of the Arabic version of HSS and WOCS-R instruments. Moreover, the pilot study was conducted to assess the items of both instruments, assess the flow of the questions, wording clarity to respondents, and practicability of the study procedure of the Arabic translated version of the HSS and WOCS-R.

Participants who agreed to participate in the pilot study and who met the eligibility based on the research proposal eligibility criteria, were asked to complete three self- administered questionnaires in Arabic. The first quantitative questionnaire consisted of basic Hemodialysis pparticipants’ characteristics (Appendix 2). The second quantitative questionnaire was Hemodialysis Stressor Scale (Appendix 3), and the third quantitative questionnaire was the Revised Ways of coping Scale questionnaire (Appendix 4). Some statements were not clear for the participants in the first pilot study, for example the majority of participants asked for the meaning of one item the

coping scale that stated: “I found a new faith”. A second pilot study was conducted (*N* =10) after modifications were done by experts to make statements clearer, for example the item mentioned above in the coping scale was modified to be “My faith became stronger”.

All encountered studies were conducted during the hemodialysis sessions, (Baldree et al. 1982; El-Lozi & Ahmed, 1994; Yeh & Chou, 2007). Patients on hemodialysis usually sleep, read, watch television, or do any activity to help ease the passage of dialysis time quickly, therefore it was convenient to complete questionnaires during dialysis session rather than at home since this means they will spend more time thinking about the problem. Participants were instructed to follow the order of the scales. Participants' names were coded as numbers and inscribed on all provided questionnaire to allow confidentiality of data treatment. All data were kept with the investigator in a locked and secured file cabinet.

Data management.

Data were entered into The Statistical Package for the Social Science SPSS, version 17, (SPSS, 2008). The data entered were printed out and double-checked against the paper and pencil copy to ensure accuracy of data entry. Data were examined using descriptive statistics to identify outliers, skeweness, and missing data. This resulted in a set of data that were replications of the paper/pencil responses to the items on each of the measures. Since the investigator made sure the questionnaires were thoroughly completed before collection, there were no missing data. Four items were omitted from responses of the single participants on the HSS since participants left those items unanswered because they were not applicable. Those items were: (reversal in family role with spouse, decrease in sexual drive, decreased ability to have children, and reversal in family roles with your children).

Data analysis.

Descriptive analysis was used to present participants' characteristics, type of stressors associated with hemodialysis, and coping strategies. Each research question is restated followed by the statistical analysis used:

1- What are the psychosocial and physiological stressors and coping strategies used among Jordanian participants with end stage renal disease on hemodialysis? Scores on the HSS were used to answer this question. The means, frequencies and standard deviations were computed and reported for the HSS total score as well as for the two physiologic and psychosocial HSS subscales.

2- What are the relationships among participants' characteristics: (Age, gender, education, marital status, number of household members, house hold income, and length of time on dialysis in years), stressors, and coping strategies in Jordanian participants with end stage renal disease on hemodialysis? The relationships among the variables for question two represent several different levels of measurement (interval and nominal). Pearson product moment correlation was utilized to examine the bivariate relationships between the variables measured with interval levels (age, number of house hold members, and length of time in years on dialysis), with stressor, and coping strategies. Point Biserial correlation was employed where one variable was nominal (gender, house hold income, education level, and marital status), and the other variable was interval (stressor, and coping strategies) (Munro, 2004).

2-Qualitative Design

This study utilized qualitative methodology from the phenomenological tradition to explore the experiences of the Jordanian patients with ESRD receiving hemodialysis, thus provided an in-depth understanding of participants on hemodialysis' stressors and coping strategies as experienced by Jordanian participants on hemodialysis. The mixing

use of both quantitative and qualitative methods is utilized to integrate research findings (Sandelowski, Voils, & Barroso, 2006). Qualitative research examines the life experiences of participants' in order to understand and give meaning to these experiences (Speziale & Carpenter, 2007). Qualitative descriptive phenomenology research utilizes a methodological framework that answers the research question and ensures reliability of the collected data and the results.

The data were collected as a complement to the quantitative study of stressors and coping among Jordanian participants receiving hemodialysis. In order to understand the phenomenon, the research question was guided by Coliazzi's philosophy of the lived experience.

Ethical Considerations.

The qualitative part of this study was approved by the Graduate Faculty Board, and Ethical Committee of the University of Jordan. Permission of a third private hospital was obtained to recruit participants. Potential participants were approached prior to hemodialysis treatment. Those who expressed interest were invited to participate. Once they agreed to participate, the methods of data collection were explained, and the participants' concerns were addressed prior arranging the interview. The participants were asked when they would like to be interviewed prior to the dialysis treatment. All participants were given a written informed consent (Appendix 5).

The participants were assured that the interviews were kept confidential. Personal data such as names were not used in the report of the study. The participants were given number codes which appeared on transcribed interviewed forms and files. Potential participants were informed of risks such as fatigue or exhaustion. Benefits of the study were also explained such as that health care team members may gain a better

understanding of patients on hemodialysis' stressors and thus plan a more effective care. In addition, they were reminded that they could stop the interview at any time or withdraw from the study without any consequences. In compliance with the University of Jordan's research policy, all tapes were destroyed after transcripts were transcribed and the transcripts and filed notes were saved in locked files with the investigator.

Sampling and Setting.

A purposeful sampling technique was employed to select participants who have experienced hemodialysis and were willing to be interviewed from a dialysis unit that was not included in the quantitative data collection. The participants were not part of the original participants' sample included in the quantitative study. A total of nine participants, five females and four males, were recruited. The five female participants were married while two of the male participants were single, and the other two were married.

Data collection.

Patients who met the eligibility criteria (same as the eligibility criteria for the quantitative study), and accepted to participate in the study received a participants' characteristics questionnaire (Appendix 2). Face-to-face semi structured interviews were conducted by the main investigator with the nine participants separately. Interviews were conducted in a private area in the dialysis unit. The confidential interviews were audio-taped and transcribed by the main investigator. During the interview, probes were used to obtain additional details. All interviews lasted between 40 to 60 minutes and were completed in 15 days. In-depth interviews aimed mainly to explore the lived experience of being on the hemodialysis.

Participants were asked to describe their lived experience of being on hemodialysis. In the course of interview, there were probes and open-ended questions to

direct the interview and to capture the stressors and coping strategies of being on hemodialysis (Appendix 6).

Data analysis.

Colaizzi's seven steps (Munhall, 2007, Marshall et al. 2010) were used in data analysis to provide a rich description of the essential structure of the phenomena. The seven steps processes of analysis were employed in this study as follows:

1. Each participant's description transcript was read in order to obtain a sense of whole.
2. Significant statements were extracted. Each transcript was examined for statements and phrases that pertain to phenomena studied. This is known as extracting significant statements.
3. Meanings from significant statements were formulated to shed light on meanings that were hidden in different contexts of the phenomenon
4. The aggregate formulated meanings were organized into theme clusters to identify the common experiences to all participants.
5. The results were integrated into a comprehensive description of the lived experience of participants.
6. Explicit statements were formulated as essential structure of the investigated phenomenon.
7. A final validation was sought from research participants. This was achieved by returning to each subject and asking the participants if the descriptive analysis was in congruence with their lived experiences.

Rigor

Analysis began by the investigator's general overview of all participants' descriptions to get a sense of the whole. The investigator read each interview several times and color coded with a highlighter the various themes for each interview. Each statement was analyzed and the significant statements that were relevant to the hemodialysis lived experiences from the highlighted statements; were cut, pasted and placed in appropriate theme areas. Each significant statement was explored, and the meaning of these selected statements was formulated. The lists of derived meanings were managed by grouping the relevant significant statements into their relevant theme cluster. These clusters checked by referring to the original statement for validation. Statements' with related and similar content and meaning were grouped together into one list of themes. The investigator wrote an exhaustive description of the lived experience of participants on hemodialysis in this qualitative study. This description was reviewed by the qualitative research expert and can be found in chapter four. Following Colazzi's steps of extracting significant statements from the interviews, these statements were reviewed by an expert in qualitative research. Ongoing data validation occurred as the investigator met with participants, reviewed their transcript and the summery of investigator's perceptions of the interview. All agreed that meanings and themes were representative.

In qualitative research, credibility is the key to develop internal validity. Application of an appropriate methodology provides the initial credibility. Additionally, recording interviews and asking participants to check transcripts for accuracy also contributes to credibility (Speziale & Carpenter, 2007). Conformability is the conception of objectivity that assesses whether the interpretation of the data could be confirmed by or substantiated by others (Speziale & Carpenter, 2007). In the qualitative

part of this study, peer debriefings took place when the investigator shared data coding categories with the other investigator who is experienced in phenomenological methodology. The themes and cluster themes were validated by the colleague and the main investigator's supervisor. During the open-end questions interviews, the investigator conducted informal member checks by asking subjects for further clarification if the investigator was unable to understand the content or the meaning of their responses to the interviews' questions. Participants reviewed the investigator's interpretation of their experience and indicated if it was accurate (Speziale & Carpenter, 2007).

Summary

This chapter presented the methodology of this study which is mixed methods of both quantitative and qualitative approaches. It has described the cross-sectional correlational design used to examine the relationship between participants' characteristics, hemodialysis stressors, and coping strategies among Jordanian participants. A convenience sample of 131 participants undergoing hemodialysis at an outpatient dialysis units located in four hospitals within the city of Amman/Jordan was used. The three self-report instruments used were the Ways of Coping Scale-Revised, the Hemodialysis Stressors Scale, and Participants' Characteristics, administered by the investigator while participants undergoing routine hemodialysis. Qualitative study has followed to describe participants on hemodialysis lived experience with hemodialysis. A purposive sample of nine patients was included in the study and each participant was individually interviewed. The interviews were audio taped and transcribed. Data were analyzed utilizing Colaizzi's (1978) method, which consists of seven steps data analysis.

CHAPTER 4

RESULTS

This chapter presents the quantitative and qualitative results of examining stress and coping strategies among Jordanian participants on hemodialysis. A description of the demographic data and correlational analysis of hemodialysis stressors and coping strategies are presented in this chapter. The results of the two research questions are presented. Firstly, descriptive statistics for the psychosocial and physiological stressors among Jordanian participants with end stage renal disease on hemodialysis are presented. Secondly, the relationships among the participants' characteristics: Age, gender, education, marital status, number of household members, household income, and length of time in years on dialysis, coping strategies, and stressors in Jordanian participants with end stage renal disease on hemodialysis are also presented. The qualitative data results, which analyze the responses from the face- to- face interviews by grouping responses into seven common themes as outlined by Colaizzi's seven steps (Munhall, 2007, Marshall et al., 2010), are also presented.

1-Quantitative Data Analysis

Participants' Characteristics

A convenience sample of patients on hemodialysis (N = 131) from four dialysis outpatient units in four hospitals in Amman- Jordan, participated in this study. There were 61.1% males (*n* = 80). The Education level was categorized into 3 groups "Elementary / Preparatory", "High School" and "Above high school" level. The highest percentage education level in the study was the "High school" group 35.1%, (*n* = 46), and the lowest was "Above high school degrees" 30.5% (*n* = 40). Approximately sixty-two percent of the participants were married (61.8%, *n* = 81) and the remaining were

single (36.6%, *n* = 48), and 1.5% (*n* = 2) were widowed. The widowed participants were excluded from the correlational analysis when marital status was included as a variable. The majority of participants were not employed (73.3%, *n* = 96). The percentage of participants who reported their household income level as acceptable (meaning just enough), was 51.7% (*n* = 73), (25.2%, *n* = 33) reported not sufficient (meaning not satisfactory) and 19.1% (*n* = 25) reported sufficient (satisfactory) income. The majority of participants dialyzed 12 hours/week (71.8%, *n* = 94). The remaining participants (28.2%, *n* = 37) received dialysis 10 hours/week. The findings are shown in Table 1.

Table 1: Frequencies, percentages for the characteristics of Jordanian participants with end stage renal disease on hemodialysis (N=131)

Item	Category	Frequency	Percentage
Gender	Male	80	61.1
	Female	51	38.9
Education	Elementary / Preparatory	45	34.3
	High School	46	35.1
	Above high school degrees	40	30.5
Marital status	Married	81	61.8
	Single	48	36.6
	Widow	2	1.5
Religion	Muslim	126	96.2
	Christian	5	3.8
Work	Yes	35	26.7
	No	96	73.3
Household Income	Not Sufficient	33	25.2
	Acceptable	73	55.7
	Sufficient	25	19.1
Days and time on Hemodialysis per week	10 hr/week	37	28.2
	12 hr/week	94	71.8

The ages of participants ranged from 18 to 77 years with mean = 46.15, SD = 15.45. No participants were excluded on the basis of their age. The mean age for the participants in the study sample was mean = 46.15, (SD = 15.45). The range of time since the start on dialysis was 6 month to 29 years with mean of 7.53 years, (SD = 6.25). The demographic data is displayed in Table2.

Table 2: Range, Means, and Standard deviations for the characteristics of the Jordanian participants with end stage renal disease on hemodialysis (N=131)

Item	Minimum	Maximum	Mean	SD
Age	18.00	77.00	46.15	15.45
Number of household members	1.00	17.00	6.61	3.14
Time since the start on hemodialysis	6 months	29 year	7.53	6.25

Stress and Coping Strategies

The first question for this study was: What are the psychosocial and physiological stressors and coping strategies used among Jordanian participants with end stage renal disease on hemodialysis? In order to answer this question, descriptive statistics were used for the analysis of both hemodialysis stress scale and the coping strategies scale.

Stress.

Means, frequencies and standard deviations were computed from the HSS. It is noted that, "Limits on time and place for vacation" with mean = 3.09 (SD =1.19) was the most frequently reported stressor. The second highest stressor was: "Limitation of fluid intake" with mean = 2.89 (SD = 1.05), "Length of dialysis treatment" had the same order as a stressor with mean = 2.89 (SD = 1.05). The lowest three means for stressors were "Limited in styles of clothing", "Reversal in family roles with your children", and "Nausea and vomiting" with means of 1.56, (SD =1.05), 1.70(SD = .88),

and 1.74 (SD = .98) respectively (Table 3). The range for the scores' means for the total scale was (1.0-3.59). In general, most of items-means show moderate level of stress. The range for the total scale scores as well as the range for both stressors subscales is presented in Table 4.

Table 3: Means, and Standard deviations (SD) for stressors among Jordanian participants with end stage renal disease on hemodialysis (N=131)

No	Item *	Means	SD
22	Limits on time and place for Vacation	3.09	1.19
5	Limitation of fluid intake	2.89	1.05
18	Length of dialysis treatment	2.89	1.04
2	**Feeling tired**	2.88	0.91
25	Loss of body function	2.78	1.20
12	Limitation on physical activity	2.76	0.93
23	Decreases in sexual drive	2.62	1.03
9	Interference with job/ working	2.60	1.30
20	Limitation of food	2.55	1.11
16	**Arterial-venous stick**	2.52	1.08
14	Changes in body appearance	2.50	1.11
11	Sleep disturbances	2.45	1.10
1	Uncertainty about the future	2.36	1.12
15	Changes in family responsibilities	2.32	1.01
26	Dependency on nurses and technicians	2.27	1.07
4	**Itching**	2.22	1.05
10	**Muscle cramps; soreness**	2.13	0.96
8	**Stiffening of the joints**	2.11	1.06
17	Cost factors	2.11	1.15
3	Decrease in social life	2.09	1.08
13	Frequent hospital admissions	2.03	1.00
19	Dependency on physicians	1.95	1.05
27	Decreased ability to have children	1.93	1.10
7	Transportation to and from the dialysis unit	1.92	1.05
21	Reversal in family role with spouse	1.82	0.88
28	Fear of being alone	1.81	1.12

No	Item *	Means	SD
6	**Nausea and vomiting**	1.73	0.98
29	Reversal in family roles with your children	1.70	0.80
24	Limited in styles of clothing	1.56	1.05

*All bold items belong to the physiological scale

Hemodialysis-related stressors were divided into two groups: physiological and psychosocial. In order to compare between the means of psychosocial stressors scores and physiological stressors scores, weighted means were used due to differences in items numbers. Findings showed that psychosocial stressors scores means were higher than the means of physiological stressors scores. Means and standard deviations for both psychosocial stressors as well as physiological stressors are presented in Table 4.

Table 4: Means, Range, and Standard deviations(SD), for stressors subscales and overall scale scores among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Hemodialysis Stressors Scale	Means	Minimum	Maximum	SD
Physiological subscale	2.26	1.5	3.83	0.62
Psychosocial subscale	2.56	1.0	2.52	0.56
Overall scale	2.3	1.0	3.59	0.49

Coping.

The mean score for coping strategies ranged from ($\bar{x}$ = 1.13, SD = 0.70) to ($\bar{x}$ = 1.91, SD = 0.51). Positive reappraisal was the highest used coping strategy followed by distancing, while accepting responsibility coping strategy was the lowest. The range mean of scores for the total scale was (0.0- 3.0). Means and standard deviations for all coping strategies items and subscales are shown in Table 5.

Table 5: Means and Standard deviations (SD) for coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=131)

No	Coping Strategies Subscales	Mean	SD
	Positive reappraisal		
36	Found new faith, (my faith in God became stronger)	2.82	0.59
60	I prayed.	2.80	0.55
56	I changed something about myself.	1.23	1.01
38	Rediscovered what is important in life.	2.17	0.89
Mean and Standard deviation for the subscale		1.91	0.51
	Distancing		
12	Went along with fate.	2.80	0.67
15	Looked for the silver lining, so to speak; tried to look on the bright side of things.	2.01	1.02
41	Didn't let it get to me; refused to think too much about it.	1.46	1.10
44	Made light of the situation; refused to get too serious about it.	1.27	1.03
Mean and Standard deviation for the subscale		1.85	0.61
	Self-controlling		
10	Tried not to burn my bridges, but leave things open somewhat.	2.33	0.94
54	I tried to keep my feelings from interfering with other things too much.	2.10	0.95
43	Kept others from knowing how bad things were.	1.10	1.15
63	I thought about how a person I admire would handle this situation and used that as a model.	0.58	0.87
Mean and Standard deviation for the subscale		1.49	0.49
	Escape-Avoidance		
11	Hoped a miracle would happen.	2.17	1.12

No	Coping Strategies Subscales	Mean	SD
58	Wished that the situation would go away or somehow be over with.	2.10	0.92
40	Avoided being with people in general.	0.74	0.96
50	Refused to believe that it had happened.	0.64	0.89
Mean and Standard deviation for the subscale		1.41	0.63
	Planful problem-solving		
49	I knew what had to be done, so I doubled my efforts to make things work.	1.64	0.96
1	Just concentrated on what I had to do next – the next step.	1.45	1.02
48	Drew on my past experiences; I was in a similar situation before.	0.99	1.03
26	I made a plan of action and followed it.	0.65	.98
Mean and Standard deviation for the subscale		1.27	0.58
	Seeking social support		
18	Accepted sympathy and understanding from someone.	1.54	0.98
22	I got professional help.	1.29	1.10
31	Talked to someone who could do something concrete about the problem.	1.05	1.04
42	I asked a relative or friend I respected for advice.	1.00	1.04
Mean and Standard deviation for the subscale		1.21	0.62
	Confrontive		
46	Stood my ground and fought for what I wanted.	2.90	0.39
28	I let my feelings out somehow.	1.22	0.96
17	I expressed anger to the person(s) who caused the problem.	0.49	0.88
34	Took a big chance or did something very risky.	0.38	0.71
Mean and Standard deviation for the subscale		1.13	0.45

No	Coping Strategies Subscales	Mean	SD
	Accepting responsibility		
51	I made a promise to myself that things would be different next time.	1.57	1.10
25	I apologized or did something to make up.	1.19	1.03
9	Criticized or lectured myself.	0.95	1.16
29	Realized I brought the problem on myself.	0.81	1.10
Mean and Standard deviation for the subscale		1.13	0.70

Stress, Coping, and Participants' Characteristics

The second question for this study was: What are the inter-relationships among the patients' characteristics (age, gender, education level, marital status, number of house hold members, house hold income, and length of time on dialysis), with coping strategies used, and stressors in Jordanian patients with End Stage Renal Disease on Hemodialysis? To answer this question, appropriate measures of association were used according to variables levels of measurement. Pearson product moment correlation was utilized to examine the bivariate relationships between the variables measured with interval levels (age, number of house hold members, and length of time in years on dialysis), with stressor, and coping strategies. Point Biserial correlation was employed where one variable was nominal (gender, house hold income, education level, and marital status), and the other variable was interval (stressor, and coping strategies), (Munro, 2004).

Age, stressors, and coping strategies.

There was no significant association between hemodialysis stressors and age (Table 6). In regard to the use of coping strategies, younger participants tended to use self-controlling and escape-avoidance strategies more than the older participants. Both

coping subscales had significant negative correlation with age (*r* = -0.25, $p \leq 0.01$) and (*r* = -0.18, $p \leq 0.05$). Correlations between coping strategies and age of the participants are shown in Table 6.

Table 6: Pearson product moment correlation between age and coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Coping Strategies Subscale	Correlation
Confrontive coping	0.04
Distancing	0.06
Self-controlling	-0.25 **
Seeking social support	-0.06
Accepting responsibility	-0.12
Escape-Avoidance	-0.18 *
Planful problem-solving	-0.11
Positive reappraisal	-0.08

** Correlation is significant at the 0.01 level (2-tailed).
*Correlation is significant at the 0.05 level (2-tailed).

Gender, stressors, and coping strategies.

Means and standard deviations for stressors according to gender are presented in Table 7. The means and standard deviations for coping strategies according to gender are presented in Table 8. Positive correlations were found between participants with physiological stressors (*r* = 0.30, $p \leq 0.01$), psychosocial stressors (*r* = 0.31, $p \leq 0.01$), and overall scale of stressor (*r* = 0.16, $p \leq 0.05$) as illustrated in Table 10. Table10 presents correlations between coping strategies and gender. Confrontive coping strategy correlated positively with gender (*r* = 0.17, $p \leq 0.05$).

Table 7: Mean and Standard deviation (SD) for stressors among Jordanian participants with end stage renal disease on hemodialysis according to gender (N=131)

Hemodialysis Stressors Scale	Male (N =80)		Female (N =51)	
	Means	***SD***	**Means**	**SD**
Physiological stressors	2.11	0.60	2.50	0.58
Psychosocial stressors	2.43	0.55	2.77	0.51
Overall scale of stressor	2.23	0.50	2.39	0.45

Table 8: Means, and Standard deviations (SD) for coping strategies among Jordanian participants with end stage renal disease on hemodialysis according to gender (N=131)

Coping Strategies Subscales	Male (*N* = 80)		Female (N= 51)	
	Means	***SD***	**Means**	***SD***
Confrontive coping	1.07	0.37	1.22	0.55
Distancing	1.89	0.64	1.79	0.57
Self-controlling	1.46	0.44	1.53	0.57
Seeking social support	1.16	0.63	1.28	0.60
Accepting responsibility	1.09	0.66	1.19	0.77
Escape-Avoidance	1.41	0.60	1.42	0.68
Planful problem-solving	1.30	0.60	1.22	0.55
Positive reappraisal	1.86	0.50	1.99	0.53

Table 9: Point Biserial correlation between gender and stressors among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Hemodialysis Stressors Scale	Correlation
Physiological stressors	0.30*
Psychosocial stressors	0.31*
Overall scale of stressor	0.16

* Correlation is significant at the 0.01 level (2-tailed).

Table 10: Point Biserial correlation between gender, and coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=13)

Coping Strategies	Correlation
Confrontive coping	0.17*
Distancing	- 0.08
Self-controlling	0.07
Seeking social support	0.09
Accepting responsibility	0.06
Escape-Avoidance	0.01
Planful problem-solving	- 0.07
Positive reappraisal	0.13

*Correlation is significant at the 0.05 level (2-tailed).

Education, stressors, and coping strategies.

There were negative correlations between education and physiological stressors (r = -0.21, $p \leq 0.05$), and psychosocial stressors (r = -0.23, p =0.01), Table 11. Three coping strategies significantly correlated with participants' education. These include seeking social support (r = -0.18, $p \leq 0.05$) and escape-avoidance strategy (r = -0.24, $p \leq 0.01$) which were negatively correlated, while planful problem-solving was positively correlated with education (r = 0.21, $p \leq 0.01$). Correlations between stressors and education level are presented in Table 12, while correlations between coping strategies and education level are presented in Table 13.

Table 11: Point Biserial correlation between education and stressors among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Hemodialysis Stressors Scale	Correlation
Physiological stressors	- 0.21*
Psychosocial stressors	- 0.23**
Overall scale of stressors	- 0.12

**Correlation is significant at the 0.05 level (2-tailed).
*Correlation is significant at the 0.01 level (2-tailed).

Table 12: Point Biserial correlation between education coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Coping Strategies Subscales	Correlation
Confrontive coping	- 0.08
Distancing	0.15
Self-controlling	0.02
Seeking social support	- 0.18 *
Accepting responsibility	0.12
Escape-Avoidance	- 0.24 **
Planful problem-solving	0.21 **
Positive reappraisal	- 0.04

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Marital status, stressors, and coping strategies.

The participants' marital status did not correlate with stressors .There was also no significant correlation between marital statuses of the participants with coping strategies. Means, standard deviations of stressors and coping strategies by marital status (single versus married) are shown in Tables 13 and table 14.

Table 13: Means and Standard deviations (SD) for stressors according to marital status among Jordanian participants with end stage renal disease on hemodialysis (N=129)

Hemodialysis Stressors	Married (n = 81)		Single (n =48)	
	Mean	SD	Mean	SD
Physiological stressors	2.30	0.64	2.17	0.57
Psychosocial stressors	2.59	0.56	2.48	0.53
Overall scale of stressor	2.30	0.53	2.27	0.40

Table 14: Coping strategies according to marital status among Jordanian participants with end stage renal disease on hemodialysis (N=129)

Coping strategies subscales	Married (*n* = 81)		Single (*n* =48)	
	Mean	SD	Mean	SD
Confrontive coping	1.17	0.47	1.03	0.38
Distancing	1.89	0.63	1.80	0.60
Self-controlling	1.44	0.45	1.60	0.53
Seeking social support	1.19	0.62	1.20	0.61
Accepting responsibility	1.14	0.70	1.14	0.71
Escape-Avoidance	1.42	0.66	1.40	0.59
Planful problem-solving	1.30	0.59	1.23	0.57
Positive reappraisal	1.90	0.53	1.92	0.50

Number of members in household, stressors, and coping strategies.

There were no significant correlations between family member number and stress in Jordanian participants with end stage renal disease on hemodialysis. There was a significant negative correlation between household member number and Planful problem-solving coping strategy (r = -0.27, $p \leq 0.01$). Correlations between coping strategies and number of family members are presented in Table 15.

Table 15: Pearson product moment correlation for number of family members and coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Coping Strategies Subscales	Correlation
Confrontive coping	0.05
Distancing	- 0.01
Self-controlling	0.04
Seeking social support	0.13
Accepting responsibility	0.05
Escape-Avoidance	0.04
Planful problem-solving	- 0.27**
Positive reappraisal	- 0.04

** Correlation is significant at the 0.01 level (2-tailed).

Household income, stressors, and coping strategies.

There were negative correlations between income and physiological stressor ($r = -0.30$, $p \leq 0.01$), psychosocial stressors ($r = -0.27$, $p \leq 0.01$), and overall Hemodialysis Stress Scale ($r = -0.35$, $p \leq 0.01$), Table 16.

Participants' income positively correlated with planful problem-solving ($r = 0.25$, $p \leq 0.01$), which means the higher income level of the participant, the more use of planful problem-solving coping strategy. Confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-Avoidance, positive reappraisal were not significantly correlated with the income level. Table 16 presents correlations between income and hemodialysis stressors while findings of correlations between coping strategies and income are shown in Table17.

Table 16: Point Bisserial correlation for stressors and income among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Hemodialysis Stressors Scale	Correlation
Physiological stressors	- 0.30**
Psychosocial stressors	- 0.27**
Overall scale of stressors	- 0.35**

** Correlation is significant at the 0.01 level (2-tailed).

Table 17: Pearson product moment correlation for coping strategies and income among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Coping Strategies Subscales	Correlation
Confrontive coping	0.03
Distancing	0.13
Self-controlling	0.06
Seeking social support	0.02
Accepting responsibility	0.03
Escape-Avoidance	- 0.16
Planful problem-solving	0.25 **
Positive reappraisal	0.09

** Correlation is significant at the 0.01 level (2-tailed).

Time on dialysis, stressors, and coping strategies.

There were no significant correlations between length of time in years on dialysis and dialysis stressors. Negative correlation were found for length of time in years on dialysis, seeking social support coping strategy (r = -0.17, $p \leq 0.05$), and accepting responsibility (r = -0.24 $p \leq 0.01$). Confrontive coping, Distancing, Self-controlling, Escape-Avoidance, Planful problem-solving, and Positive reappraisal were not significantly correlated with the participants' length of time in years on dialysis. Findings of correlations between coping strategies and length of time in years on dialysis are presented in Table 18.

Table 18: Pearson product moment correlation for length of time in years on dialysis and coping strategies among Jordanian participants with end stage renal disease on hemodialysis (N=131)

Coping Strategies Subscales	Correlation
Confrontive coping	- 0.20
Distancing	- 0.06
Self-controlling	0.04
Seeking social support	- 0.17*
Accepting responsibility	- 0.24**
Escape-Avoidance	- 0.17
Planful problem-solving	- 0.14
Positive reappraisal	- 0.06

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

2-Qualitative Data Analysis

The third question for this study was: What is the lived experience of Jordanian patients with End Stage Renal Disease on Hemodialysis? To answer this question, Colaizzi's seven steps (Wojnar & Swanson, 2007, Munhall, 2007, Marshall et al. 2010) were used in data analysis to provide a rich description of the essential structure of the phenomenon.

The in-depth analysis of the transcripts led to seven major emerging themes. The themes include; (1) Life style changes, disruption of jobs, and daily living activities; (2) Hours spent in dialysis deprived them of their family and social life; (3) Challenges of physiological symptoms and the dialysis procedures add to the stressors of the dialysis participant; (4) Disrupted marital, family and social life, and self-esteem; (5) Inability to fulfill Religious and spiritual commitments; (6) Hope, Spiritual beliefs, family friends play a major role in their lives; and (7) Health care providers are sources of support.

1) Life style changes, disruption of jobs, and daily living activities

All participants were suffering from the changes in their previous lifestyle that was imposed on them as a result of their illness and dialysis. Most of them discussed food and fluid restrictions as a significant stressor associated with their illness. Most participants reported practicing continuous attempts for compliance to restrictions to avoid any life threatening side effects. Most of the participants indicated that with the passage of time, they became adapted more to the fluid and diet restrictions. However this restriction imposes a constant challenge to them on a daily basis, particularly in social occasions. Participants described their experience with the fluids and food restrictions. One participant, a 39 year old male explained:

"Fluid restrictions are one of my biggest problems. I suppress my desires to drink, I try to take some ice or take little amount of juice if my blood sugar level is low… plus I feel thirsty all the time, I love drinking water and tea as you know tea is our favorite drink with breakfast I barely drink tea any more as I used and I miss it."

Another participant said:

"I have minimized my visits to friends and relatives because I do not want tell them I cannot drink tea or juice because of my dietary restrictions."

The same participant continued to describe how those restrictions affected his food preferences:

"I used to be able to eat all types of food and now everything is forbidden except some boiled salt free foods, and who can eat constantly and like such food", " used to love eating Mansaf (cooked dry yogurt) every Friday, and now I have to control myself not to eat much. The yogurt is salty fluid that makes me want to drink more water. Mansaf was my favorite dish, I used to eat it frequently, but now things are different."

A female participant of 39 years, also described how physically and emotionally she has to continuously deal with fluid restrictions. She felt a sense of deprivation and resentment that she can't drink as she used to before her disease saying:

"My problem is I love to drink lots of water, no one can drink as much as I used to. I try to comply but I still come to dialysis with three and one-half to five liters of excess fluid. It is a continuous stress for me; I can't decrease my urge for drinking fluids"

All of the nine participants identified hemodialysis as a barrier to vacation and limited them from social activities. Hemodialysis made it hard for them to travel even short distances to other cities in Jordan unless they arrange to have dialysis in the place they visit. The younger and working participants were more affected by the restraints of movement while on hemodialysis. A 46 year old female participant explained:

"I have a daughter in the United Arab Emirates; it is hard to visit her because I will need to be dialyzed there and the treatment needs a lot of money."

Furthermore, another participant commented:

"If you want to go anywhere you can't go for a long period of time, thus it being a burden I bear. If I go on Thursday, I have to be back on Saturday."

Since the participants were all adults in their productive years, one male participant revealed that his physiological symptoms influence his ability to keep a job or change it and even sometimes it is difficult for him to find a job that facilitate his attendance of dialysis sessions. Unemployment is a stressor associated with dialysis for

young adults. Some of the reported issues related to jobs included statements by a 50 year old lecturer and trainer who used to be active and travel a lot:

"I know now that I can't work like before because of the dialysis sessions, I also stopped travelling like before. I know I can't be away more than a day."

In addition, a 39 year old participant explained how the dialysis affected his job:

"I used to be the head of a department but now due to my dialysis sessions, I work as an ordinary employee and they don't give me important things to do. I can't work a full shift; I used to work from 8 am to 6 pm."

Another 38 year old male participant described how he had to stop working after being on long term hemodialysis and the affect it had on him socially and emotionally:

"One of the biggest problems that hemodialysis caused for me, is the loss of my job and that I can't work anymore. This affected me psychologically and socially and affected many things in my family life as well as relations with my wife. I used to dialyze in Kuwait at first because that is where I used to work. Then I had to leave from there because I lost my job due to illness and I had to come back to get free dialysis treatment in Jordan. I tried to look for a job in Amman but I didn't find any because there is no one who will hire a dialysis patient who has to leave work 3 days a week to go for his treatment. Also, I can't use my right arm at work anymore; it got weaker after the fistula surgery was done."

The participants agree that their symptoms contributed to the disruption in their daily activities. Most of the participants reported their inability to carry out their regular daily activities such as carrying out house chores, personal hygiene and perform prolonged activities that they used to carry out, without taking rest in between. The decrease in functional capacity was reported by most of the participants as evidenced in the following quotes:

"Thank God I have my daughters, I give them instructions to prepare a meal but I am not able to reach the kitchen to do it myself."

Another 39 year old participant expressed the weakness he felt after dialysis sessions:

"The body loses salts and minerals with dialysis, I feel like a deflated balloon and feel like a burden since I can't be helpful."

2) Hours spent in dialysis deprive them from their families and social life

The participants' indicated that hemodialysis takes long hours, is very exhausting and tiring. Participants also explained, how being on dialysis for four hours, three times a week, plus the time in transportation is a waste of time. Participants become focused on clock time and are unable to engage in their daily activities. Embedded in their time count they develop anger, frustration, and tiredness. The time spent on dialysis also makes the participants spend less time with their family and added to that the fact that they feel very tired after dialysis makes the days of dialysis difficult for performing their family roles. Working and socially active participants find it also difficult to go to work on the dialysis days or continue with the social activities they used to have before being dialysis participants. This great inconvenience was expressed by a 39 year old participant describing his experience of time wasted on dialysis days:

"I calculated the time I wasted for the dialysis and found that 60% of my time is wasted because of the hemodialysis. The time includes two hours transportation to the dialysis unit back and forth, as well as the time spent there; three to four hours, then the time it takes to get home, by then I can't do anything for me. I feel tired and exhausted which means I need the whole day to rest, I can't do anything else, and that day is wasted." "This has been going on year after year"

3) Challenges of physiological symptoms and the dialysis procedures add to the stressors of the participants.

Participants undergoing hemodialysis usually have many disturbing physiological symptoms related to the chronic renal failure and treatment side effects. Most participants in this study described physiological symptoms such as muscle cramps, headaches, nausea, and fatigue as expressed in the extract below by a 56 year old female participant:

"After dialysis I get headaches, sometimes nausea, as well as the cramps I get in my legs and all my body pains. I feel so exhausted, weak, and on the top of that I can't move as before. I have no energy to walk or stand in the kitchen." Another 46 year old

female participant suffered from hypotension post dialysis that affected her health. She described this state saying: “After dialysis sessions, my blood pressure goes down and this makes me dizzy and I sleep till next morning.”

Arterial-Venous fistula needle stick to obtain access for hemodialysis is also a challenge for some dialysis participants. As far as needle sticks, the more years the participant had needle sticks on dialysis, the lesser this issue was reported as stressful. A 56 year old participant who was on hemodialysis for 2 years and has a new A-V fistula expressed feeling severe pain some times during the needle sticks:

“Sticks are painful; I can't get used to them. I feel tortured while they put dialysis needles in my arm, because my veins and arteries are narrow. Due to my suffering from needle sticks, I thought seriously about kidney transplant to get rid of the pain they cause me.”

However, 56 year old female participant who was on hemodialysis for 5 years described how the needle sticks are not causing her much pain any more:

‘”When I first started dialysis, needle sticks used to hurt me a lot. Now after repetition of sticks in my fistula I don't feel the pain any more, it was as if the nerves stopped feeling anything in that part of my arm.”

4) Disrupted marital, family and social life, and self-esteem

Some Participants admitted having a conflict in their family roles and relations after being on hemodialysis as this statement by a 46 year old married female explained:

“Thank God I have a very caring family but unfortunately sometimes this care upsets me because I feel weak and less independent as I used to be. Sometimes I feel disappointed, I feel I shouldn't be dialyzing and giving my children any trouble.”

There were also markedly revelations of a disruption in their sexual relationship in hemodialysis lived experiences. Both male and female participants reported a decrease in libido related to hemodialysis. This change was expressed in statements such as this statement by a 50 year old married male participant:

“Since eight months ago my wife became like a sister since sexual relations are nonexistent. This is a very sensitive matter for me as a man. Erection is what makes the difference between being a man or not.”

Another 56 year old married female participant expressed sexual dysfunction in her marital relation:

"I have less sexual desires than before; I think I am not the only dialysis patient with this problem since I hear other patients complaining of the loss of sexual function as well. I told my husband he can marry another woman if he likes since I am not interested in sex anymore."

Moreover, many of the participants expressed how being on long term dialysis has greatly disrupted their social relations making them socially isolated, and therefore do not take part in social event or avoid social activities as well. As one 39 year old male participant had expressed these changes:

"Simply, patients on dialysis have psychosocial stressors. Socially they withdraw from society as well as their usual jobs."

Additionally, another 39 year old female also emphasized this social change:

"I was very busy with many social activities, my time was occupied with friends and my children and I had a wonderful life but after being a dialysis patient, it seemed as if someone dropped me down from sky to earth."

Some dialysis participants also depend on other family members to keep social relations with extended family members and friends when they are unable to do it themselves. A female participant of 64 years explained this change:

"I can't go shopping or visit people like before, therefore I ask my daughters and daughter's in-law to carry out the social relations and duties on my behalf. For example, in occasions such as weddings and celebrations they do these social duties instead of me."

Moreover, all participants were married except for two young male participants. One of the single participants; a 24 year old male expressed being stressed out by the fact that illness and treatment were obstacles to getting married:

"No father of a girl would like his daughter to be married to a sick man like me. Every father likes his daughter to be happy, not suffer in her life with a dialysis patient."

5) Inability to fulfill Religious and spiritual commitments

Maintaining spiritual commitments is an important aspect in the lives of dialysis participants as spirituality is proven to help participants with chronic illnesses cope with their disease. For the Jordanian participants on hemodialysis, prayers and other religious activities like going to Makah and fasting the Holy month of Ramadan gives them the strength not only to accept their long term disease, but also deal with the daily challenges they face. However the dialysis routine interferes with the participants' desire for maintaining their religious commitments. Participants expressed how dialysis affected the travel to Makah and Medina for Omrah or Hajj. A 39 year old male participant stated:

"I used to go for Omrah every year but since I started dialysis I couldn't go, it needs a lot of arrangements to guarantee dialysis treatment in another country."

Also, a 64 year old female explained how she also faced difficulties to go for Omrah:

"I wasn't able to go to Makah to perform Omrah when I started dialysis. Later, I was told I can arrange to have dialysis in Makah if I plan to go for Omrah. I took this chance and made the most of this opportunity, so I went last year."

Furthermore, another religious issue that is greatly affected by being on dialysis is fasting during the Holy month of Ramadan. Patients on hemodialysis are not supposed to be fasting on dialysis days due to the treatment and on the other hand they may feel weak to fast on non dialysis days. This can make it a stressful time for them, not being able to do the religious ritual as they used to do before their disease, affects them emotionally. They feel strong and close to God when fasting, not doing the ritual upsets them, as they feel they are not being able to connect with God. This is expressed by a 39 year old male:

"I tried to fast few days in Ramadan, but most days I couldn't fast, I feel I am missing out."

6) Hope, Spiritual beliefs, family friends play a major role in living with dialysis

Kidney transplant, when feasible, is an option for some participants on hemodialysis that give them hope that dialysis treatments will no longer be required. This was pertinent only to two participants, a 39 year old male and a 38 year old female. Both participants did all tests needed to get a transplant from a donor and are waiting for final approval of their doctors. They described their feelings about that in statements such as:

"I needed a heart surgery so that I could have kidney transplant and I went through that surgery to repair a heart valve. Then I was told I have many antibodies so I had to wait till the antibodies count becomes low. Now my doctor told me that I may be able to have the transplant in couple of months. I am living on hope after I put my trust in Allah." The other participant stated: "I am hoping to have kidney transplant even if I couldn't get a relative donor. I, among 40 other young dialysis patients, wrote an appeal to the government to facilitate kidney transplant for us and other patients. I live with great optimism and hope, Allah's mercy is great, for I rely on him through the good and bad."

There were strong revelations by participants that faith was the most important factor that helped them in dealing with their disease and treatment. Prayers and reading verses from the Qur'an encouraged them to adapt to medical problems and positively manage their situations. Most participants felt more connected with God this way and feel most secure relying on him. Below are some quotations from the participants:

A female participant of 64 years stated:

"Thank God, I am a believer in Him and I adapted to my situation. I read the Holy Quran many times in Ramadan. Today, I read a part in the Holy Quran before I came for dialysis. I convinced my kids that this is a test from God and the believer should pass this test and accept God's will."

Also, a 56 year old participant stated:

"Praying a lot and worshiping God makes the person feel he is in the circle of God's care."

A 39 year old male explained as well:

"My relation with God has increased, I don't miss any prayer time, and I pray when I am emotionally upset or when I can't sleep. I have submitted to God and his

saying Do not hate something that could be good for you and do not love something that could be bad for you."

Furthermore, relations with family were another factor that was expressed by participants as important in dealing with their disease. This is illustrated in the excerpts by a 46 year old married female participant:

"Faith in God and the support of my children made it easier for me to cope with my condition."

"My husband and children are always standing by me."

The support of household members is important factor in helping participants cope with the long term demands of the dialysis treatment. One female explained how living as extended family helped her to cope with ESRD and hemodialysis stressors:

"My husband died in 1984 and left me with 11 children. Thank God all are married and most of them are living in same apartment building. They all respect me and help me when I need them." She added "I have no problem in travelling back and forth to dialysis unit. They all share the responsibility of driving me to get there and back home with pleasure."

Another 46 year old female participant also emphasized on the support she gets from spouse, children and sibling:

"My husband and children are very supportive, even my eldest brother offered me his kidney for transplant. Their support raised my spirits up and decreased the agony I suffer from my disease and treatment." She added "my children are competing with each others that who can help and serve me more, they all want to please me."

More details about the family role in alleviation of suffering were expressed by a 56 year old married female participant who described the help of her daughters who are still living at home:

"It is getting harder for me to move around or do any house chores. My daughters are the ones who cook and wash dishes; I can't do much with my arm where the dialysis shunt present.

"She added**:**

"My husband is a very special man, very generous, caring, and supportive. Thank God I have him by my side; I say not everything has to be perfect in this life."

Also, another 39 year old unmarried male participant explained how the support of friends and health care members helped him cope with dialysis:

"All my friends like me, one of them even lives with me since I moved from Irbid to Amman for work and dialysis"

7) Health care providers are sources of support; still more needs to be done

Dialysis patients stay many hours in dialysis units where they spend at least 10-12 hours a week and interact with many health care providers, specifically nurses. The relationship with doctors and nurses, regarding the care and support they receive is important in the lives of these patients. According to the participants, it makes their dialysis less stressful and enables them to have the patience to go through with the routine and procedures. One single male participant describes his relation and expectations from the nursing staff:

"The nurses are very supportive, there is a young nurse, and he cracks jokes and makes me laugh. The nurses can help a lot in making the patients less anxious about their condition, by creating a high spirited environment and procedures become accepted and less of a routine."

Some participants expressed appreciation for the health care team efforts but thought that there is a lot more that could be done to help patients on hemodialysis in dialysis units. A male participant stated:

"Nurses do their job putting us on the machine, but there should be more than that. Nurses should know how to communicate with the dialysis patients, I mean the art of communicating not just doing the routine procedure each time we come to the dialysis unit. They should know how to deal with others in regards to treating the patients as humans not robots. Also, briefing the patients and debriefing them is vital and of great importance. They should educate the patients how to recognize when their blood pressure is low or high and explain to the patient the importance of completing the four dialysis hours each time not just wanting to finish dialysis in three hours and go home. The patients should be educated that it is very important to dialyze the prescribed time till the end of the dialysis session."

The same participant also emphasized the importance of the role of nutritional education for the dialysis patients and that more attention should be given to this issue since it could seriously affect the life of the hemodialysis patient saying:

"Nutritional information should be explained thoroughly to the patients on hemodialysis many times so that they know the importance of adherence to the prescribed diet. Many of my dialysis friends died because their blood potassium level was very high and they were eating the wrong food. I mean even if I am an educated dialysis participant, I still need to be reminded frequently about food restrictions for my condition, what to eat and what to avoid."

Summary

This chapter presented the results for descriptive statistics, and exploratory analysis conducted for this study. One hundred and thirty-one participants undergoing hemodialysis were included in this study to determine the psychosocial and physiological stressors among Jordanian patients with ESRD on hemodialysis, and the relationships among patients' characteristics (age, gender, education level, and marital status, number of house hold members, house hold income, and length of time in years on dialysis), coping strategies, and stress. Findings of the quantitative study showed that hemodialysis psychosocial stressors were more prevalent than physiologic stressors (Table 4), with the most frequently reported stressors being "Limits on time and place for vacation", "Limitation of fluid intake," "Length of dialysis treatment"and"Feeling tired." Of the eight coping strategies subscales, the mean score for positive reappraisal subscale was the highest.

For the collateral qualitative study, individual interviews were conducted with nine participants on hemodialysis. Colaizzi's seven steps analysis were applied and seven categories were identified, which explained the lived experiences of participants on hemodialysis. Overall findings indicated that the Jordanian patients on hemodialysis are more likely to use adaptive coping strategies and most importantly, the result indicated that religious coping was the most used strategy. The results of the data analysis are discussed in detail in the following chapter.

CHAPTER 5

DISSCUSION

This chapter presents a discussion of the study's results in four principal sections: Interpretation of the findings from both mixed methods parts related to the research questions with associated patients' characteristics, summary for mixed methods, implications for nursing, and limitations of the study. Recommendations for future research and conclusion will follow.

The primary purpose of this mixed descriptive, cross-sectional correlation design study was to facilitate an understanding of the hemodialysis associated stressors and the subsequent coping strategies in patients on hemodialysis. The study also explored how patients on hemodialysis had described their hemodialysis stressors and how they had coped with these stressful life situations. Each research question is discussed and a summary of findings is presented. Moreover, the discussions of the quantitative and qualitative findings are combined to provide a more in-depth view of the hemodialysis stressors and coping strategies among patients on hemodialysis. The conceptual model of the study was drawn from Lazarus and Folkman (1984) cognitive theory of stress and coping.

In order to be able to recruit the sample number needed for this study, the investigator had to visit the different dialysis units at different times since the there were three dialysis sessions during one day for different patients. Patients came to the dialysis unit early morning, afternoon, or evening. Some patients preferred to sleep as soon as they get on the dialysis machine, so the investigator waited till they wake up to be able to ask them if they would like to participate in the study.

The first research question was ‘what are the psychosocial and physiological stressors among Jordanian patients with End Stage Renal Disease on Hemodialysis?’

This study found that psychosocial stressors were perceived more than physiological stressors (Table 4). Several studies reported hemodialysis physiological and psychosocial stressors (Baldree et al., 1982; El-Lozi & Ahmad, 1994; Mok & Tam, 2001; Lok, 1996; Welch & Austin, 1999; Logan et al., 2006; Cinar et al., 2009). The findings of this study were consistent with El-Lozi, Lok who reported that psychosocial stressors were more prominent than physiological stressors, and Mok and Tam also found the mean score of psychosocial stressors to be higher than the mean of physiological stressors. The cultural sensitivity is possibly a factor influencing the increased perceptions of psychosocial stressors. Since the Jordanian culture is family centered, and people tend to visit with friends and loved ones.

Stressors associated with hemodialysis reflected how participants’ perceive the treatment process. This study showed the highest ranked stressor was “limits on time and place of vacation”, a finding consistent with Logan et al. (2006) and Cinar et al. (2009). However, limit on time and place for vacation was not the highest ranked stressor identified in another study (Yeh et al., 2007). The finding is supported by the collateral qualitative study done for the purpose of this dissertation where it was found that participants experienced an inability to schedule hemodialysis treatment in areas where they are intending to visit and sometimes the cost for the treatment session is too high. The high rating given to this item may be related to the age of the study participants and their retirement status and also their loss of jobs. During face to face interviews, participants were planning to visit family members living abroad, and some of those participants had more time for travel and vacation. Making frequent visits to close family members was of high importance to them.

Other sources of stress arise from the dialysis course of therapy such as fluid restriction and attending the treatment. “Limitation of fluid intake” was the second most troublesome factor to the patients. This finding was supported by other investigators who cited “Limitation of fluid intake” as the most common stressor component of treatment (Baldree et al., 1982; Gurklis & Menke, 1988; Welch & Austin, 1999; Mok & Tam, 2001; Logan et al., 2006). Patients are confronted with a small amount of fluid that is allowed to be consumed. This could be more stressful on them than feeling thirsty. Thirst is a physiological feeling that is originated in the thirst center in the hypothalamus located in the brain (McKinley & Johnson, 2004). Confronted with fluid restriction, as part of treatment regimen, is problematic for many patients. Face-to-face interviews revealed that participants were concerned that when socializing with friends or relatives they were unable to drink hot tea, coffee, and juices, which are the most popular drinks in Jordan. According to the Jordanian hospitality norms, refusing the offered drink is considered impolite. As a supplement to the quantitative findings, the qualitative findings in this study described how almost all participants agreed that fluid restriction is a major stressor:

“I feel thirsty all the time”, “I can't decrease my urge for drinking fluids”, “I suppress my desires to drink.”

The treatment stressors such as dietary and fluid restriction usually go together. In this study, fluid restriction was more prominent and caused isolation from friends and family by minimizing social visits.

In addition, “Length of dialysis treatment” proved to be just as much of a stressor as “Limitation of fluid intake” even more than feeling tired. This finding was consistent with Welch and Austin (1999), but was in contrast to Logan et al. (2006) who found that the length of dialysis treatment was the lowest ranked stressor. Participants in this study revealed that their lived experiences with hemodialysis indicated that there was

time lost in regards to the time needed to go back and forth to the dialysis unit, and the time the patient was physically connected to hemodialysis machine. The time lost was related to the inconvenience of the location of the dialysis unit, the travel time back and forth to the dialysis unit, and the decreased social life while actually getting the hemodialysis treatment. The hemodialysis units were lacking in social activities, and there was an inability to involve oneself in cherished activities (Moran, Scott, & Darbyshire, 2009). This finding has shed some light on the importance of working with participants to make their time in dialysis more productive by providing significant activities which would make dialysis treatment less stressful.

It is a common feeling for the ESRD patient to experience tiredness and lack of energy before and after hemodialysis treatments. This particular stressor ranked fourth among all stressors which was a consistent finding with other studies (Baldree et al., 1982; Welch & Austin 1999; Mok & Tam, 2001; Cinar et al., 2009). A possible explanation for the high rating of this stressor in this study may be that the fatigue affected other aspects of family and social life. For example, lack of energy may have hindered participants from engaging in family, social or physical activities and events.

The range of stressors participants reported was (1.0 -3.59) as indicated in (Table 4). The least stressful scale items included fear of being alone, nausea and vomiting, reversal in family roles with children, and limited in styles of clothing. Participants in this study tended to rate items which they have no control over as the most stressful problems.

Although the results of this study revealed that participants on hemodialysis used all coping strategies subscales, the majority of the participants had used emotion-focused strategies. The study findings showed that participants mainly favored the positive reappraisal strategy followed by distancing strategy. In turn, any stressors

participants may experience could be seen as an opportunity for personal growth rather than as an inconvenient stressor.

The positive reappraisal coping strategy characterized as either emotion-focused or problem-focused and could be further described as, “efforts to create positive meaning by focusing on personal growth, and it has also a religious meaning” (Folkman & Lazarus, 1988, p. 11). Even though positive reappraisal is considered one of the emotion-focused strategies, Folkman and Lazarus explained that positive reappraisal is also a problem-focused coping strategy which is “strategies that are directed at motivational or cognitive changes such as shifting the level of aspiration, reducing ego involvement, or finding alternative channels of gratification” (Lazarus & Folkman, 1984, P. 152). For patients with chronic illness such as ESRD and who are dependent on hemodialysis, it is necessary to reflect on the situation to be able to adapt to it.

The high reporting of the use of the positive reappraisal coping strategy may be due to Religion. “I prayed” is an item under positive reappraisal on the WOCS-R scale. Prayers and reading verses of the Holy Quran had been also utilized by most of the participants in the qualitative study. Religion was considered as a source of strength to deal with hemodialysis stressors, and a way of comfort that improved life. However, it has been documented in literature that coping strategies could be influenced by situational demands such as the irreversibility of chronic illness and the irreversible associated treatment (Larsen & Morof Lubkin, 2008), the cultures (Yeh, Huang, & Chou, 2008) and societies’ rules of the perception of stressors (Lazarus & Folkman, 1984), and religious orientation (Carone Jr & Barone, 2001).

The second coping strategy participants on hemodialysis utilized in this study was coping through distancing from hemodialysis-related stressors. Distancing is considered an emotion-focused coping mechanism which includes convictions such as,

"Accept it, since nothing can be done", "I feel that time will make a difference", and "I'm waiting to see what will happen before doing anything." This particular finding was consistent with Mok and Tam (2001) who reported, that in the Chinese culture, the most common coping strategy was to "accept the situation because very little could be done", and "told oneself that the problem was really not that important." Such strategies measures cognitive efforts to distance patients from the disease and its adverse effects of the hemodialysis treatment in order to disengage or minimize the impact of the stressful situation. It appears that most participants on hemodialysis in this study distance themselves from the disease and the adverse effects of the treatment most of the time, perhaps due to the irreversibility of ESRD or the medical treatment. However, under high levels of related stressors, it may not be impossible to distance oneself from these stressors. Participants' on hemodialysis in this study exercised combinations of coping strategies using positive reappraisal and distancing. These methods are seemingly agreeable with the Jordanian culture beliefs where by people believe in God's Will and that praying is a way to bring comfort and calm.

Previous research suggested that healthier coping strategies such as problem focused coping strategies should be encouraged, but when facing chronic illness the chance of the patient using an emotion focused method which involves distancing, is expected to be a harmful way to cope. Folkman and Moskowitz (2000) argued that emotion-focused coping helped to shield against stressors and increased psychological well-being and health. In this study positive reappraisal and distancing resulted in acceptance and positive reinterpretation which are two examples of positive emotion coping strategies and helped participants with coping even under stressful situations. The potential influence of the Jordanian cultural background, the burden of

hemodialysis symptoms, and the coping methods of the participants are warrant to further investigation.

The total scores of WOCS-R ranged from (0 to 198), with higher scores indicating a greater use of coping strategies. Participants in this study had used all eight subscale coping strategies, but the majority had used emotion-focused strategies. Lazarus and Folkman (1984) provided a possible explanation for the predominant emotion-focused coping. They assumed that emotion focused method are more relevant across different situations, while problem focus method is situation specific. However, patients on hemodialysis experience a number of treatment related stressors. The increased perception of high rate of stress and pervasive lack of ability to control the stressors lead to psychosocial stressors. Thus, patients feel the need for employing more coping strategies especially emotion-focused strategies. In contrast, problem-focused coping is employed when patient perception of the stressors can be handled and with less psychosocial stressors.

The second research question was **"**What are the inter-relationships among the patients' characteristics (age, gender, education level, marital status, number of house hold members, house hold income, and length of time on dialysis), with stressors and coping strategies in Jordanian patients with End Stage Renal Disease on Hemodialysis?"

Age variable was not significantly correlated with stressors in this study which is congruent by Baldree et al (1982). Among the most important results are the coping strategies of younger participants utilizing self-control and escape-avoidance strategies which are different from other participants whose overall coping strategies favored positive- reappraisal and distancing, (Table7). Self-control strategy describes efforts in an attempt to regulate one's feelings such as "I tried to keep my feelings to myself'' or

"Kept others from knowing how bad things were", as well as an actions as a result of the feelings such as "I tried not to act too hastily or follow my first hunch" or "Tried not to burn my bridges, but leave things open somewhat" (Folkman & Lazarus, 1985). On the other hand, the escape-avoidance strategy, describes wishful thinking such as, "Wished that the situation would go away or somehow be over with", or "hoped a miracle would happen" and efforts to escape or avoid the stressors such as, "Tried to make myself feel better by eating, drinking, smoking, etc" or, "Avoided being with people in general" or "Slept more than usual" (Folkman & Lazarus, 1985). Folkman et al. (1987) found younger people used "confrontive coping, seeking of social support, planful problem solving" (p. 182) which involve problem-focused forms of coping. Bagheri-Nesami, Rafii, and Oskouie (2010) reported emotion-focused strategy which includes self-control and escape-avoidance strategies were employed to cope with age related changes.

Apparently younger Jordanian participants with ESRD on hemodialysis seemed to utilize self-controlling and escape-avoidance coping strategies in an attempt to control their emotions and avoid confrontation with stressors. Self-controlling and escape-avoidance also may serve as a method of refraining from negative internal feelings and reducing the harm caused by hemodialysis related stressors (Folkman et al., 1987).

Perceptions of physiological and psychosocial hemodialysis stressors were more prevalent in women than in men (Yeh, Huang, Chou & Thomas, 2009). When examining the correlations between participants' characteristics, physiological stressors, and psychosocial stressors, the findings of this study have shown that women reported greater physiological and psychosocial stressors than men. A finding that was consistent with this study was El-Lozi and Ahmad (1994) which found that Jordanian women

reported higher psychological hemodialysis stressors than men. It appears that Jordanian women in this study were more likely to report and talk about stressors either physiologic or psychosocial more than men in an attempt to mobilize social support from family members, neighbors, and friends. Another factor could be that since women in Jordanian culture are the ones' who take over the house chores such as cooking, cleaning, socializing with relatives and friends they will understandingly report more stressors. In the qualitative study, the five female participants expressed a conflict in family roles and relations:

''Thank God I have my daughters, I give them instructions to prepare a meal but I am not able to reach the kitchen to do it myself''.

Another female participant expressed how her role in the family was reversed because of the hemodialysis:

"I can't go shopping or visit people like before, therefore I ask my daughters and daughter's in-law to carry out the social relations and duties on my behalf. For example, in occasions such as weddings and celebrations they do these social duties instead of me."

Research about relationship between gender, stressors, and coping strategies had yielded some inconsistent findings in the literature. Baldree et al. (1982), and Mok and Tam (2001) reported no relationship between the gender and hemodialysis stressors. Studies of researchers such as (Yeh & Chou, 2007; Mok & Tam, 2001; El-Lozi & Ahmad, 1994) have shown gender differences in coping strategies with hemodialysis for example women usually employ emotion-focused or support seeking strategies, while men use more of the avoidance strategies. Yeh and Chou (2007) reported women had higher stress scores in physiological symptoms. Mok (2001) reported no relationship between the gender and coping strategies. The findings of the study were different from the previously mentioned study in that there is a significant relationship between gender and hemodialysis stressors among participants on hemodialysis. This

study revealed that women had used confrontive coping behavior which is characterized as a problem-focused coping behavior. Confrontive coping is described as efforts to alter the situation that is perceived as harm (Lazarus & Folkman, 1984). It is interesting to note that women in this study had adapted the secondary appraisal approach. They had evaluated the stressful situation and employed strategies eagerly to alter the situation. However, confrontive coping strategy is described as an unskillful confrontation that may not be useful in eliminating the stressors (Lazarus & Folkman). This finding makes it warranted to further future investigation of the coping strategies used by Jordanian female patients on hemodialysis

There were negative correlations between education and hemodialysis stressors (Table 12). This indicates the higher the education level of the participant, the less likely they were to report psychosocial and physiological stressors. Moreover, one recent study revealed that the higher the level of education, the better the level of psychosocial coping (Akpabio, Uyanah, Osuchukwu, & Samson-Akpan, 2010). This finding suggested that the higher the education level of the patient, the least apt they are to report physiologic and psychosocial stressors. In regards to coping strategies and educational level, Lazarus and Folkman (1984) had considered educational level as a personal resource that influences the individuals' coping strategies. This study revealed that educated participants were less likely to use “seeking social support” and “escape-avoidance” coping strategies than participants with lower education, and that participants with a higher education level found planful problem-solving strategies for coping to be more effective.

Planful-problem-solving can be defined as purposely putting efforts to change and improve the situation in congruence with an analytic approach to problem solving. However, this strategy is problem-focused, indicating participants’ acceptance of the

situation which makes them less likely to report physiological and psychosocial stressors. The findings in this study suggested that educated participants on hemodialysis take direct action to solve their problems when perceived a stressful situation (secondary appraisal) as harmful. The fact that participants with a lower education chose to use seeking social support and escape-avoidance coping strategies with hemodialysis stressors is an interesting finding; since some items of seeking social support includes, “Talked to someone to find out more about the situation” or “Talked to someone who could do something concrete about the problem.” These statements are in contrast to the escape-avoidance coping strategy which includes statements such as, “Avoided being with people in general” or “Took it out on other people.” The possible explanation for this could be that these participants’ personal resources such as education level were minimal, which makes them feel that they have no control over their treatment related stressors. Moreover, participants search for different coping resources such as seeking social support including seeking information, tangible support, and emotional support. This leads to the conclusion that higher education level is an important factor in coping with hemodialysis stressors.

The role of marital status on perceived psychosocial stressors has been discussed in the literature (Rambod & Rafii, 2010; Shortridge & James, 2010). The findings of this study suggested that no significant differences exist between unmarried and married participants and their perception of stressors. In the qualitative study statements from both married and single, participants were expressing different issues that caused their stress. For the married it could be related to the fact that patients are not able to maintain normal sexual relations with their partners. One 56 year old married female participant expressed sexual dysfunction in her marital relation:

“I have less sexual desires than before; I think I am not the only dialysis patient with this problem since I hear other patients complaining of the loss of sexual function

as well. I told my husband he can marry another woman if he likes since I am not interested in sex anymore." Another male participant stated: "Since eight months ago my wife became like a sister since sexual relations are nonexistent. This is a very sensitive matter for me as a man. Erection is what makes the difference between being a man or not."

For the single participants, stressors could be related to the fact that their future as spouses and parents is no more the same after being on chronic hemodialysis. One single participant; a 24 year old male explained the fact that illness and treatment were obstacles to getting married:

"No father of a girl would like his daughter to be married to a sick man like me. Every father likes his daughter to be happy, not suffer in her life with a dialysis patient."

Although there were no single female participants in the qualitative study, the hemodialysis has also a major role in the lives of single females. The physiological changes that take place in the female's reproductive system after being on chronic hemodialysis can make it harder to plan for getting married and having children. This finding is consistent to Mok and Tam (2001) who found no significant differences in the degrees of psychosocial stress between married and unmarried subjects.

Few studies had documented the correlation between house hold family members' number and coping strategies with hemodialysis. Conley, Burton, DeNour, and Wells (1981), and Rambod and Rafii (2010) reported that major sources of support for dialysis patients were family members. However, social support from participants' families as indicated in the qualitative part of this study was one of the key coping resources that the Jordanian participants on hemodialysis rely on. The number of participants with children in this sample is relatively large at an average of 6.61 children. Jordanian culture regards mutual rights and obligations of the spouse, children, and sibling to provide support to parents' brothers and sisters. One female participant stated:

"My husband and children are very supportive, even my eldest brother offered me his kidney for transplant."

However, the quantitative findings showed no significant correlations between the number of family members and hemodialysis stressors. There was a negative correlation between number of house-hold members and the planful problem-solving coping strategy. Explanation may be that according to Jordanian culture, the sick family member is nurtured and expected to assume a passive role in family matters. When a family member suffers from chronic illness such as ESRD, the other members in the family are expected to provide the care and support needed. Nevertheless, numerous lifestyle changes encounter patients living with hemodialysis treatments, thus the support of family members cannot be underestimated.

This study also examined the relationship between income level and hemodialysis stressors. Results suggest that there were negative correlations between income and physiological stressor (r = -0.30, $p \leq 0.01$), psychosocial stressors (r = -0.27, $p \leq 0.01$), and overall Hemodialysis Stress Scale. In the qualitative study interviews, many participants expressed being unable to work and earn living any more. One 38 year old male participant described his experience in this regard:

"One of the biggest problems that hemodialysis caused for me, is the loss of my job and that I can't work anymore. This affected me psychologically and socially and affected many things in my family life as well as relations with my wife. I used to dialyze in Kuwait at first because that is where I used to work. Then I had to leave from there because I lost my job due to illness and I had to come back to get free dialysis treatment in Jordan. I tried to look for a job in Amman but I didn't find any because there is no one who will hire a dialysis patient who has to leave work 3 days a week to go for his treatment. Also, I can't use my right arm at work anymore; it got weaker after the fistula surgery was done."

When coping with chronic illness and hemodialysis in particular, financial issues are significant since participants lose their jobs due to limitations when attending hemodialysis treatment, consequently, affecting coping strategies. Findings in this study revealed that the higher income level of the participant, the more is the use of planful

problem-solving coping strategies. This suggests that participants utilized secondary appraisal, and took direct action to alter the stressful situation indicating they were using problem-focused coping strategies. Brantley, Erin, O'Hea, Jones, and Mehan (2002) found that the middle income sample participants endorsed planful problem solving.

Length of time in years on dialysis had been investigated as a variable in hemodialysis stressors and coping strategies. Coping strategies were influenced by length of time that a patient has been receiving dialysis. It was found that the longer had the participants been on hemodialysis, they tend to use less of the "seeking social support" and "accepting responsibility" as coping strategies (Table 23). Accepting responsibility is defined as one realizing their own responsibility in the problem-solving strategies (Folkman & Lazarus, 1988) with a related theme of trying to put things right such as "Criticized or lectured myself." Jordanian participants on hemodialysis tended to reevaluate the hemodialysis stressors and reappraise how to respond right. The participants in this study were focused on food and fluid restrictions, medication regimen, and the need to attend dialysis session regularly. This finding contradicted what Mok and Tam, (2001) found, they reported no significant associations between length of time on dialysis and coping strategies and treatment-related stressors. Mok explained that "patients have become accustomed to the dialysis routine and established their coping behaviors" (Mok & Tam, 2001, p. 510). In consistence with Baldree et al. (1982), Gurklis and Menke (1988), and Mok an Tam studies' findings, the results in this study indicated there were no significant correlations between length of time on hemodialysis and hemodialysis stressors.

The third question in this study was "What is the Lived Experience of being on Hemodialysis?"

Valuable descriptions and insights were collected from the participants regarding their hemodialysis stressors and coping. Participants were generally experienced about both physiological and psychosocial hemodialysis stressors. The seven themes described the major stressors as: vacation limitation, time consumed by dialysis, fatigue after dialysis, life style changes, disruption of jobs, daily living activities, and food and fluid restrictions. The findings of this study validate stressors reported by previous studies (Bapat et al., 2009; Kaba et al., 2007; Hagren et al., 2004; Harwood et al., 2005). Jordanians enjoy family and social events, such as going out visiting families and friends, chatting, sipping juice, coffee and tea, eating sweets, fruits, and mixed roasted nuts and water melon seeds. These activities contradict with ESRD dietary prescription and participants apt to stay home and minimize all their social activities which make their life socially restricted and isolated.

Time spent on hemodialysis had an impact on the participants life style, which is consistent with (Kaba et al., 2007) who described the time on hemodialysis as “little space for living” (p.871) and ‘not finding space for living’ (Hagren et al., 2004, p. 296). For Jordanians, hemodialysis is time consuming. The time spent for the hemodialysis treatment, was competing with their personal life and so their social activities were affected. They also feel eliminated from their daily activities which lead to restrictions in their life. It was obvious that participants were experiencing difficulties in keeping up with their social life. This is illustrated in one of the statements by the participants regarding this issue:

“I was very busy with many social activities, my time was occupied with friends and my children and I had a wonderful life but after being a dialysis patient, it seemed as if someone dropped me down from sky to earth.”

For some participants, household roles and marital relations had been adversely affected. Similar findings to this study were also reported by other studies (Namiki,

Rowe & Cooke, 2009, Bapat et al., 2009, & Al-Arabi, 2006). These findings include loss of familiar roles, dependence on family members to take over the social events, feeling isolated, and the disruption of sexual relations. Some of the statements expressing these stressors include:

"I can't go shopping or visit people like before, therefore I ask my daughters and daughter's in-law to carry out the social relations and duties on my behalf. For example, in occasions such as weddings and celebrations they do these social duties instead of Me."; and: "Since eight months ago my wife became like a sister since sexual relations are nonexistent. This is a very sensitive matter for me as a man. Erection is what makes the difference between being a man or not."

The coping strategies participants used most in this study were emotion-coping, which included acceptance of the restrictions, hence "get used to it"; relying on others for help such as adults or children, spouses and siblings, dialysis staff ; and praying. Participants believe in the power of praying and faith as a strategy of coping. The participants were concerned about fulfilling religious duties as an important factor for coping with ESRD and its treatment. This concern could be explained of the importance of praying and faith in helping participants to redefine and reappraise potential stressors in ways that seem less stressful and less threatening and diverting attention from treatment stressors. Similarly, other studies had shown that coping with hemodialysis was associated with increased prayer and relying on God gives peace of mind (Walton, 2002), the ability to cope with restricted social life (Burns, 2004) and accepting the illness (Walton, 2002). The findings in this study are also consistent with Ano and Vasconcelles (2005), who indicated religious coping, had been associated with improved psychological adjustment to stressors including serious illness. The role of religion in the coping with the disease was expressed in statements such as:

"Thank God, I am a believer in Him and I adapted to my situation. I read the Holy Quran many times in Ramadan. Today, I read a part in the Holy Quran before I came for dialysis. I convinced my kids that this is a test from God and the believer should pass this test and accept God's will." And: "My relation with God has increased, I don't miss any prayer time, and I pray when I am emotionally upset or when I can't

sleep. I have submitted to God and his saying Do not hate something that could be good for you and do not love something that could be bad for you."

Overall, the study has found that culture and religion influenced participants' coping. Both were viewed as a means for the participants to reevaluate their lived experience and accept the unavoidable chronic illness and treatment and use them as coping strategies.

Mixed Methods Summary

This study had used mixed methods approach presented in data collection, analysis and integrated findings offering a glimpse of the potential use of such investigation in hemodialysis as chronic illnesses. The mixed methods uncovered hemodialysis stressors, prevailed coping strategies, examined stress coping theory and provided comprehensive evidence of hemodialysis stressors and coping.

Quantitative and qualitative data had been gathered sequentially. The use of sequential explanatory mixed method was tended to examine whether the qualitative data would support the quantitative data. The supplemental qualitative study aimed to verify and capture the lived experience of the patients on hemodialysis. The findings which were driven by quantitative and qualitative approach answered the research questions. The qualitative findings played a prevailing role in completing, confirming and adding collective knowledge to the findings beyond the scope of single method technique.

In the qualitative study, nine participants were included to describe their lived experience with the disease. The different themes that emerged not only gave more depth to the findings of the quantitative study, but also clarified some points answered in the scale that were not rated to reflect the real situation. An example is that participants had frequent comments in open-end-interview such as:

"Sticks are painful", "needle sticks used to hurt me a lot…now after repetition of sticks in my fistula I don't feel the pain any more".

The low rating of "arterial-venous stick" could be related to lack of participants' consideration of the pain accompanying the stick since the statement did not clarify that. Pain could be added to the item "arterio-venous fistula stick" so that it will be "pain from arterio-venous fistula stick."

An example of how the qualitative findings confirmed the quantitative findings in this study is that participants indicated that limitation of travel and visits was an important stressor affecting their lives. An example is this statement by a participant in the qualitative study**:**

"If you want to go anywhere you can't go for a long period of time, thus it being a burden I bear. If I go on Thursday, I have to be back on Saturday."

In regard to coping strategies, the most frequent coping strategy on WOCS-R subscale was positive reappraisal which includes the statement" I prayed." In assertion to that, in the open-end-question interviews, participants frequently reported relying on God to give them strength needed to cope with hemodialysis stressors as well as improving their health. The findings provide support to Cinar et al. (2009) and Sakhaei and Radfar (1999) who concluded that the coping method against hemodialysis stressors was through faith in God and the religious beliefs. This mixed methods study also gave the opportunity to gain more insight of patients on hemodialysis concerns not mentioned in the HSS. An example of that is what a participant in the face-to-face interviews expressing feelings of the dialysis patients in dialysis units and how they would like to be treated and educated by nurses:

"Nurses do their job putting us on the machine, but there should be more than that. Nurses should know how to communicate with the dialysis patients, I mean the art of communicating not just doing the routine procedure each time we come to the dialysis unit. They should know how to deal with others in regards to treating the patients as humans not robots. Also, briefing the patients and debriefing them is vital and of great importance. They should educate the patients how to recognize when their

blood pressure is low or high and explain to the patient the importance of completing the four dialysis hours each time not just wanting to finish dialysis in three hours and go home. The patients should be educated that it is very important to dialyze the prescribed time till the end of the dialysis session."

And another participant commented regarding nutritional concerns:

"Nutritional information should be explained thoroughly to the patients on hemodialysis many times so that they know the importance of adherence to the prescribed diet. Many of my dialysis friends died because their blood potassium level was very high and they were eating the wrong food. I mean even if I am an educated dialysis participant, I still need to be reminded frequently about food restrictions for my condition, what to eat and what to avoid."

Finally, the use of the mixed methods in this study proved to be very powerful not only for the purposes of findings and in-depth analysis, but also it did help in gaining more insight of the importance of refining WOCS-R scale that reflect more of the Jordanian society where studies are conducted.

Limitations, Implications, and Recommendation,

Based on the findings of this study, this section presents implications for nursing research, education, practice, and policy, recommendations, and the limitations of the study.

Limitations

1- The convenience sample for this study represents four dialysis units in the capital. This sample did reflect the capital population demographics and responses but did not include other units from other geographic areas in the country which may limit the representation of the overall hemodialysis population.

2- This study is a cross sectional correlation design. This design does not address whether stressors and coping strategies change over time in relation to demographic characteristics.

Implications

Implication for nursing research.

The findings of this study may contribute to more focus on the impact of hemodialysis treatment stressors on patients. The findings of this study may help also in leading the research to focus more on coping from religious perspective.

Implication for nursing education.

Based on the findings of this study, nurse educators should communicate with students in the classroom and clinical settings the significance of recognizing hemodialysis stressors and the coping strategies used. Emphasis should be directed toward the importance of more coordination of care for the patients on hemodialysis.

A holistic model related to the hemodialysis patient care which incorporates all human needs in the physiological, psychosocial and spiritual aspects of patients into nursing assessment and intervention should be promoted. Educators should also integrate the conceptual model of stressors and coping strategies in the curricula and plan nursing education curricula to include an educational module on holistic care that includes spirituality, faith, and prayers as part of nursing education.

Implication for nursing practice.

The findings give direction to nurses working with patients on hemodialysis with helpful information on being attentive to patients on hemodialysis' feelings and educational needs as well their stressors and how they manifest. Since stressors reflect the patients concerns it would be prudent to prepare individualized interventions that address the patients' concerns related to their treatment, help them to minimize stressors, enhance their coping strategies, and eliminate some of the more persistent hemodialysis stressors.

In addition, the coping strategies for each patient should be identified and more adequate information should be given to facilitate the patient's coping needs. The results of this study can be applied by planning individualized teaching programs for patients. To facilitate this planning process, the study findings can be used in nursing education in the clinical settings by teaching nurses about stressors and the coping strategies that patients on hemodialysis have found to be effective. Special focus should be placed on the trend that a patient's preference of coping and their effectiveness is often situation-dependent. As evident from the findings of the study, the demographic characteristics of patients such as age, educational level, and marital status and their living environment is what influenced the type of coping strategy or strategies used.

In regard to age and the coping strategies used, it would be beneficial for nurses and other health care professionals who are working with younger patients to pay attention to the manifestation of the coping strategy these patients are using.

Furthermore, when assessing patients on hemodialysis, it is important to be conscientious of the patients' educational level. Encourage them to be part of the planning process by helping them to express their feelings about the current interventions, and based on patient's feedback seek alternative interventions if possible. Additionally, in order to enhance coping resources, encourage the involvement of spouses, family members, and significant others in various aspects in patients care. The findings of the study indicated that "Limits on time and place for vacation" was a top perceived stressor by a Jordanian patient receiving hemodialysis. It is important to help patients, spouses, and family members to plan appropriate recreational programs and family visits to help patients cope with this particular treatment stressors.

The qualitative study revealed that participant's family members play a major role in helping them so it is important to provide an ongoing assessment of patients'

perceived changes in level of support regarding their family members and friends. Nurses should also be aware of patients' physiological limitations (e.g. fatigue, weakness, sleep) and incorporate these symptoms in the care plan to facilitate the best possible physiological functioning for patients on hemodialysis.

As the findings showed, Jordanian patients on hemodialysis rely on religious belief in coping with a stressful situation. Patients with religious faith helped them cope with demands of hemodialysis. Praying has been identified as a coping strategy that almost all participants employed when dealing with treatment stressors. Emotion-focused coping, which included “I prayed”, is an item under positive reappraisal on the Ways of Coping Scale. It is important to incorporate the religious aspect into the patients’ comprehensive care plan. The presence of a religious counseling in hospitals could aid in facilitating such care plan.

Moreover, nurses can encourage the psychosocial coping of patients on hemodialysis by evaluating and enhancing resources and coping strategies. It is important to give patients the opportunity to express their feelings and concerns. Since reappraisal is a component of the Stress and Coping Model, stressors and coping strategies are often changed and should be reassessed frequently since hemodialysis is a long life treatment. Scheduling a time for some discussions between the nurse and the patients may enable them to converse freely about their treatment stressors and enhance their coping strategies. Overall, an understanding of the cultural differences in perception of hemodialysis stressors and associated coping strategies to living with hemodialysis can provide a strong basis for nursing interventions that can help improve coping strategies.

Implications for policy makers.

Dialysis units nursing managers and other health team members can utilize the findings of this study to establish a policy for the development of an assessment tool for the dialysis units to enable for the continuous assessment of the stressors affecting long-term dialysis patients and the coping strategies used.. An interdisciplinary approach can be adopted in the application of this policy and for the follow up and monitoring for the effectiveness of the coping strategies used by these patients. A coordinator for the application of such policy on each patient should be assigned.

Recommendations

In general, this study examined perceived hemodialysis stressors and coping strategies at a specific point in time. A longitudinal study is recommended and data collection may start from the time of diagnosis with ESRD to six months after starting hemodialysis and then on a yearly bases. This method of research may relate information about factors that influence a patient's perception of certain hemodialysis stressors and the ways of coping that reflect a patient's specific experience at various time periods on hemodialysis.

Further research should be done to focus on the stressors in regard to marital status. The HSS apparently did not reflect the magnitude of the stressors single and married patients have. However, the qualitative interviews results shed the light on issues that need addressing for both single and married patients on hemodialysis.

Investigation of the relationships among perceived stressors and preferred styles of coping should be done. Findings of such studies may help nurses to have information they need to design appropriate stress and coping assessment in the context of the patients' experience and implement the appropriate intervention to improve the health status of patients on hemodialysis.

In regard of the distinctive different social, culture, and marital role of Jordanian men and women, future research regarding the perception of stressors and coping strategies might be conducted separately for each gender. Finally, future research regarding the Jordanian culture as a factor affecting hemodialysis stressors and coping strategies would be beneficial. The findings in this study indicated that religious issues should be considered when investigating coping strategies in this Arab- Muslim society.

Conclusion

The purpose of this quantitative and qualitative study was to investigate hemodialysis stressors and ways of coping among Jordanian participants through administration of Hemodialysis Stressors Scale, Ways of Coping Scale-Revised, and using the Phenomenology approach to explore their lived experience on hemodialysis. The study results demonstrated that Jordanian participants perceive psychosocial stressors more than physiologic stressors and limits on time and place of vacation was the highest ranked stressors, followed by limitation of fluid intake. The preferred coping strategy was emotion-focused which involved Positive Reappraisal and Distancing as an opportunity for personal growth rather than as a means to address stressors. Young participants favored self-control coping strategies and escape-avoidance coping strategies in an attempt to control their emotions and avoid confrontation with stressors.

In regard to hemodialysis stressors, the qualitative results mostly supported the quantitative findings. This congruency was also evident for the preferred coping strategies. The items “I Pray”, and “My faith in God became stronger” from the positive appraisal coping strategy, and the qualitative study findings revealed that participants rely on praying as a way of coping with hemodialysis stressors. The findings of this study add to the body of knowledge on patients on hemodialysis’ physiological and

psychosocial stressors and how they cope with their stressors. Further research is needed to verify the suitability of the WOCS-R to chronic illnesses in Arab- Muslim culture and to increase reliability of the subscales. These findings have significant implications for the nurses actively caring for patients on hemodialysis, and for nursing education.

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APPENDICES

Appendix1

نموذج موافقة على المشاركة في دراسة

ضغوطات غسيل الكلى وطرق التعامل معه

عنوان الدراسة: فحص ضغوطات غسيل الكلى وطرق التعامل / التكيف ، بين الاردنيين اللذين يعانون من فشل كلوي ويستخدمون جلسات غسيل الكلى

اهداف الدراسة: 1 - فحص الضغوطات الفسيولوجية والضغوطات النفسية- الاجتماعية الناتجة عن غسيل الكلى عند الاردنيين اللذين يعانون من الفشل الكلوي ويستخدمون جلسات غسيل الكلى.

2- فحص العلاقة بين مستوى ضغوطات غسيل الكلى وطرق التعامل / التكيف ، بين الاردنيين اللذين يعانون من فشل كلوي ويستخدمون جلسات غسيل الكلى .

ماذا عليّ أن أفعل؟: تحتوي هذه الدراسة على 3 استبيانات استطيع إكمالها خلال جلسة غسيل الكلى حسب راحتي وبـإمكاني إكمالها في جلسة تالية .المدة التي تستغرقها تعبئة هذه الاستبيانات تتراوح بين 20-30 دقيقة.

ضمان السرية: كل المعلومات المقدمة لغرض هذه الدراسة ستعامل بسرية تامة واسمي لن يعرّف به بأي وقت. ولن يطلع على هذه الاستبيانات إلا الباحث الرئيسي والمشرف على البحث.

الأخطار: لا توجد أخطار تنتج عن المشاركة في الدراسة ، ربما يحصل بعض الإرهاق الجسدي أوالنفسي عند البعض أثناء تعبئة الاستبيانات ويحق لي أن أتوقف إذا شعرت بالإرهاق آو عدم الرغبة بالاستمرار.

منافع البحث: النتائج ربما ستساعد العاملين في المجال الصحي على تفهم أكثر للضغوطات الفسيولوجية والنفسية- الاجتماعية للأفراد اللذين يعانون من الفشل الكلوي وهم على جلسات غسيل الكلى.

الفوائد والحرية الشخصية بالانسحاب من الدراسة: يمكنني الانسحاب في أي وقت من الدراسة بدون أية عواقب. يمكنني الاستفسار عن أي سؤال في الاستبيانات. قراري بالمشاركة في الدراسة أو عدمها لن يؤثر على علاج غسيل الكلى المقدم لي في هذا المستشفى.

تصريح بالموافقة: أن تعبئة الاستبيانات لهذه الدراسة تعني موافقتي على أن أكون احد المرضى المشاركين في هذا البحث الذي تقوم به إيمان النزلي طالبة الدكتوراه / كلية التمريض/ الجامعة الأردنية.

مع جزيل الشكر على مشاركتكم في الإجابة على استبيانات هذه الدراسة.

عنوان الباحث: إيمان النزلي/ طالبة دكتوراه / كلية التمريض في الجامعة الأردنية

المشرف: دكتور مؤيد احمد/ كلية التمريض / الجامعة الأردنية هاتف: 5355000 / فرعي 23131

Appendix 2

الخصائص الشخصية لمريض غسيل الكلى

1 - **الجنس**: أنثى ☐ ذكر ☐

2- **العمر**:-------

3- **المستوى التعليمي**

- ابتدائي ☐ إعدادي ☐ ثانوي ☐ دبلوم ☐ بكالوريوس ☐ دراسات عليا☐

4- **الحالة الاجتماعية:**

- متزوج ☐ - أعزب ☐ - أرمل\أرملة☐

–عدد أفراد الأسرة---------------

- عدد الأولاد: ذكور----------- إناث----------

5- **الديانة**: مسلم☐ مسيحي☐

6- **أعمل:** نعم ☐ لا ☐

7- نوع العمل----------------------

- عاطل عن العمل☐ متقاعد☐ ربة منزل☐

8- **دخل العائلة**: غير كافي ☐ مقبول☐ كافي ☐

9- **مسببات الفشل الكلوي المزمن**

- مرض السكري ☐

- ارتفاع الضغط ☐

- أمراض الكلى ☐

10- أسباب أخرى للفشل الكلوي -----------------------

11 - عدد السنوات (الأشهر) منذ بدء مرض الكلى : سنة------ شهر------

12- هل يوجد أمراض أخرى --------------------------

13- المدة منذ البدء على غسيل الكلى: سنه-------- شهر:-----------

14- أيام الأسبوع الخاصة بجلسات غسيل الكلى:------------------------------------

Appendix 2

Demographics of the Hemodialysis patient

1-Gender: Male ▢ Female▢

2-Age: -------------------

3-Education:

Elementary▢ Preparatory▢ High school▢ Diploma▢ college ▢ Graduate ▢

4-Marital status:

Married▢ Single▢ widow▢

Number of household members: -------------

Number of children: Males------------- Females------------------

5-Religion: Muslim▢ Christian▢

6-I work: yes▢ No▢

7-type of work: -----------------------

Not working ▢ Retired ▢ housewife▢

8-Household Income: Not Sufficient▢ Acceptable▢ Sufficient▢

9-Causes of Chronic renal Failure:

Diabetes▢ Hypertension▢ Kidney Disease

10-Other caused for renal Failure: --

11- Number of years since the beginning of Renal disease: Years--------

Months------

12-any other diseases: --------------------------------

13- Time since the start on Hemodialysis Treatment: Years--------

Months----------

14-Days and time on Hemodialysis per week--------------------

Appendix 3

مقياس ضغوطات غسيل الكلى

يرجى الإجابة على كل من البنود التالي لمدى تأثير كل بند على حياتك من ناحية الضغوطات الناتجة عن المعالجة بالغسيل الكلوي حسب المقياس التالي:

1- لا مطلقاً
2- قليلاً
3- بشكل متوسط
4- كثيراً

علماً بأنه لا يوجد إجابة صحيحة و إجابة خاطئة

#		لا مطلقا	قليلاً	بشكل متوسط	كثيراً
.1	غموض أو تشوش بشأن المستقبل.	1	2	3	4
.2	الشعور بالتعب.	1	2	3	4
.3	انخفاض العلاقات الاجتماعية.	1	2	3	4
.4	أعاني من الحكة الجلدية.	1	2	3	4
.5	يضايقني الحد من شرب السوائل	1	2	3	4
.6	الإحساس بالغثيان والتقيؤ	1	2	3	4
.7	صعوبة الذهاب إلى وحدة الغسيل والعودة منها.	1	2	3	4
.8	تصلب أو تشنج في المفاصل	1	2	3	4
.9	التأثير على الوظيفة او العمل	1	2	3	4
.10	الإحساس بالتشنج العضلي والالم.	1	2	3	4
.11	أعاني من الاضطرابات في النوم.	1	2	3	4
.12	الحد من النشاط الجسدي	1	2	3	4
.13	الدخول المتكرر الى المستشفى	1	2	3	4
.14	أشعر بتغير في مظهر الجسم	1	2	3	4
.15	أشعر بتغير في المسؤوليات العائلية	1	2	3	4
.16	يضايقني الوخز بالابر في بداية جلسة الغسيل	1	2	3	4
.17	تضايقني التكلفة المادية للمرض	1	2	3	4
.18	يضايقني طول وقت جلسة الغسيل	1	2	3	4
.19	تضايقني الحاجة الى الاعتماد على الأطباء	1	2	3	4
.20	يضايقني التقيد بالحمية الغذائية	1	2	3	4
.21	عكس الأدوار بين الزوجين	1	2	3	4
.22	قيود على زمان ومكان اخذ العطلة/ التنقل/ السفر	1	2	3	4

#		لا مطلقا	قليلاً	بشكل متوسط	كثيراً
.23	أعاني من انخفاض الرغبة الجنسية.	1	2	3	4
.24	إلزامي بزي محدد من الملابس اثناء الجلسة العلاجية.	1	2	3	4
.25	اضطرابات بعض وظائف الجسد الحيوية مثل التبول وغيرها.	1	2	3	4
.26	أجد نفسي مضطراً للاعتماد على الممرضين والفنيين أثناء جلسات الغسيل.	1	2	3	4
.27	أشعر بانخفاض في القدرة على الإنجاب	1	2	3	4
.28	الخوف من الوحدة	1	2	3	4
.29	عكس الأدوار العائلية مع الأبناء والبنات.	1	2	3	4

Appendix 3

HEMODIALYSIS STRESSORS SCALE

Please read each of the following items and then rate on the scale below, how much you believe each item is currently affecting your life in a stressful way.

1= not at all	**2= slightly**	**3= moderately**	**4= a great deal**		
1	Uncertainty about the future	1	2	3	4
2	Feeling tired	1	2	3	4
3	Decrease in social life	1	2	3	4
4	Itching	1	2	3	4
5	Limitation of fluid intake	1	2	3	4
6	Nausea and vomiting	1	2	3	4
7	Transportation to and from the dialysis unit	1	2	3	4
8	Stiffening of the joints	1	2	3	4
9	Interference with job/ working	1	2	3	4
10	Muscle cramps; soreness	1	2	3	4
11	Sleep disturbances	1	2	3	4
12	Limitation on physical activity	1	2	3	4
13	Frequent hospital admissions	1	2	3	4
14	Changes in body appearance	1	2	3	4
15	Changes in family responsibilities	1	2	3	4
16	Arterial-venous stick	1	2	3	4
17	Cost factors	1	2	3	4
18	Length of dialysis treatment	1	2	3	4
19	Dependency on physicians	1	2	3	4
20	Limitation of food	1	2	3	4
21	Reversal in family role with spousal	1	2	3	4
22	Limits on time and place for vacation	1	2	3	4
23	Decreases in sexual drive	1	2	3	4
24	Limited in styles of clothing	1	2	3	4
25	Loss of body function	1	2	3	4
26	Dependency on nurses and technicians	1	2	3	4

1= not at all	**2= slightly**	**3= moderately**	**4= a great deal**		
27	Decreased ability to have children	1	2	3	4
28	Fear of being alone	1	2	3	4
29	Reversal in family roles with your children	1	2	3	4

Appendix 4

طرق التعامل/ التكيف مع المرض

منذ أن تلقيت خبر وجوب بداية العلاج بواسطة جلسات الغسيل الكلوي ، الرجاء الإجابة على الأسئلة التالية التي تهدف للحصول على معلومات حول الطرق التي تستخدمها للتعامل مع الضغوط الناتجة عند الخضوع لهذا النمط من العلاج حسب المقياس التالي:

0: نادرا

1: احيانا

2: غالبا

3: دائما

علماً بأنه لا يوجد إجابة صحيحة و إجابة خاطئة

#	السؤال	نادرا	أحيانا	غالبا	دائما
1-	ركزت فقط على ما يجب أن أقوم به في المرحلة المقبلة.	0	1	2	3
2-	حاولت أن احلل المشكلة من اجل تفهمها بطريقة أفضل.	0	1	2	3
3-	لجأت إلى العمل، أو تشتيت انتباهي عن الأمور التي تجول في ذهني.	0	1	2	3
4-	شعرت أن الوقت كفيل بالتغيير – الشيء الوحيد الواجب فعله هو الانتظار.	0	1	2	3
5-	حاولت الانتظار آملاً في الوصول إلى ما هو إيجابي في الوضع الحالي	0	1	2	3
6-	قمت بعمل، على الرغم من اعتقادي بأنه لن ينجح، لكنني قمت على الأقل بفعل شيئا ما.	0	1	2	3
7-	حاولت إقناع الطبيب المعالج بتبديل رؤيته في وضعي المرضي.	0	1	2	3
8-	تحدثت مع بعض الناس للتحقق أكثر من وضعي الصحي.	0	1	2	3
9-	ألقيت اللوم على نفسي.	0	1	2	3
10-	لم استسلم لليأس، وأبقيت الباب مفتوحا للأمل.	0	1	2	3
11-	تمنيت حدوث معجزه لحل المشكلة.	0	1	2	3
12-	أمنت بقضاء الله وقدره.	0	1	2	3
13-	تابعت العمل والعلاج وكأن شيء لم يكن.	0	1	2	3
14-	حاولت إخفاء مشاعري.	0	1	2	3
15-	بحثت عن بصيص أمل وحاولت النظر إلى الجانب الإيجابي للأمور.	0	1	2	3
16-	لجأت إلى النوم لمدة أطول هرباً من التفكير بمشكلة المرض	0	1	2	3
17-	وجهت غضبي إلى الشخص / الأشخاص الذين اعتقدت أنهم تسببوا في المشكلة.	0	1	2	3
18-	تقبلت تعاطف بعض الناس وتفهمهم.	0	1	2	3
19-	قلت لنفسي أشياء ساعدتني في الشعور بشكل أفضل.	0	1	2	3
20-	فكرت بحلول جديدة للتعامل مع المشكلة	0	1	2	3
21-	حاولت نسيان كل شيء مرتبط بالمرض.	0	1	2	3

#	السؤال	نادرا	أحيانا	غالبا	دائما
-22	تلقيت المساعدة من شخص متخصص.	0	1	2	3
-23	أرى أنني نضجت وتغيرت للأفضل من الناحية الشخصية.	0	1	2	3
-24	انتظرت لأرى ما قد يحصل، قبل أن أقرر فعل شيئا ما.	0	1	2	3
-25	حاولت القيام بأشياء للتعويض عما حدث معي.	0	1	2	3
-26	عملت خطة ونفذت تفاصيلها.	0	1	2	3
-27	قبلت بالحل الأفضل للوضع الحالي المناسب لما أريده.	0	1	2	3
-28	أفصحت عن مشاعري بعض الشيء.	0	1	2	3
-29	أدركت بأنني جلبت المشكلة لذاتي.	0	1	2	3
-30	خرجت من التجربة بحال أفضل مما كنت عليه قبلاً	0	1	2	3
-31	تحدثت إلى أحد الأشخاص، لعله يعمل ما يساعدني على حل مشكلتي.	0	1	2	3
-32	تجاهلت المشكلة لبعض الوقت، حاولت أن أستريح أو اخذ إجازة.	0	1	2	3
-33	لم أتقيد بتعليمات ألحميه الغذائية (أو أسرفت في التدخين) لتحسين شعوري النفسي	0	1	2	3
-34	جازفت و قمت بأفعال قد تعرضني للخطر.	0	1	2	3
-35	حاولت أن لا أتصرف بتهور كبير أو القيام بخطوه غير مدروسة.	0	1	2	3
-36	زاد إيماني بالله عزوجل.	0	1	2	3
-37	حافظت على كبريائي ولم استسلم.	0	1	2	3
-38	بدأت اكتشف ما هو مهم في الحياة.	0	1	2	3
-39	أجريت بعض التغيرات في حياتي لعل الأمور تتغير نحو الأفضل.	0	1	2	3
-40	تجنبت تواجدي مع الناس بشكل عام.	0	1	2	3
-41	رفضت التفكير بالمسألة ، ولم ادع المشكلة تؤثر علي.	0	1	2	3
-42	طلبت نصيحة قريب أو صديق أكن له احتراماً.	0	1	2	3
-43	أخفيت عن الآخرين مدى سؤ وضعي الصحي.	0	1	2	3
-44	قللت من أهمية الوضع ورفضت إعطائه الأهمية الكبيرة.	0	1	2	3
-45	تحدثت مع احد الأشخاص عن ما كنت اشعر به.	0	1	2	3
-46	تمسكت بإيماني، وتوكلت على الله بالشفاء.	0	1	2	3
-47	نفستُ عن غضبي لقاء إصابتي بالمرض بعدة وسائل .	0	1	2	3
-48	تعلمت من تجاربي السابقة، فقد مررت بإحداث مشابهه في الماضي.	0	1	2	3
-49	عرفت ما يجب القيام به لذا ضاعفتُ جهودي لإنجاح الأمور.	0	1	2	3
-50	رفضت الاعتراف بأن هذه المشكلة قد حدثت.	0	1	2	3

دائما	غالبا	أحيانا	نادرا	السؤال	#
3	2	1	0	عاهدت نفسي بأن أتعامل مع المشكلات التي تواجهني بطريقة مختلفة في المستقبل.	-51
3	2	1	0	استخدمت عدد من الحلول للتعامل مع المشكلة الحالية.	-52
3	2	1	0	قبلت بالأمر الواقع، إذ ليس في اليد حيلة.	-53
3	2	1	0	حاولت السيطرة على مشاعري.	-54
3	2	1	0	تمنيت لو كان باستطاعتي تغيير ما حدث أو ما شعرت به آنذاك.	-55
3	2	1	0	غيرت شيئاً ما في ذاتي.	-56
3	2	1	0	لجأت إلى أحلام اليقظة، والتصور بأنني في مكان وزمان أخر.	-57
3	2	1	0	تمنيت لو يزول أو ينتهي الوضع.	-58
3	2	1	0	حصلت لي تخيلات أو امنيات حول مستقبل المشكلة.	-59
3	2	1	0	صليت وقمت بالدعاء.	-60
3	2	1	0	تحضرت للأسوأ بالنسبة لوضعي الصحي.	-61
3	2	1	0	فكرت فيما يجب أن أقوله أو اقوم به.	62
3	2	1	0	فكرت كيف يمكن أن يتصرف شخص أخر إذا كان مكاني واستخدمه كمثل لي.	-63
3	2	1	0	حاولت أن أنظر الى الأمور من منظار أخر.	-64
3	2	1	0	حاولت تذكير نفسي أنه من الممكن للأمور بأن تكون أكثر سوءاً.	-65
3	2	1	0	مارست الرياضة البدنية.	-66

مع جزيل الشكر على مشاركتكم في الإجابة على استبيانات هذه الدراسة

Appendix 4

WAYS OF COPING (Revised)

You were told that you will need sooner or later to be started on hemodialysis, and then you were started on this treatment. Now that you have experienced hemodialysis for at least 6 months, please answer the following questions which aim to obtain knowledge on how you have managed to cope with hemodialysis stressors.

Please read each item and rate your answers according the following scale:

0=Not used	**1=Used somewhat**	**2=Quite a bit**	**3=A great deal**		
1	Just concentrated on what I had to do next – the next step.	0	1	2	3
2	I tried to analyze the problem in order to understand it better.	0	1	2	3
3	Turned to work or substitute activity to take my mind off things.	0	1	2	3
4	I felt that time would make a difference – the only thing to do was to wait.	0	1	2	3
5	Bargained or compromised to get something positive from the situation.	0	1	2	3
6	I did something which I didn't think would work, but at least I was doing something	0	1	2	3
7	Tried to get the person responsible to change his or her mind.	0	1	2	3
8	Talked to someone to find out more about the situation.	0	1	2	3
9	Criticized or lectured myself.	0	1	2	3
10	Tried not to burn my bridges, but leave things open somewhat.	0	1	2	3
11	Hoped a miracle would happen.	0	1	2	3
12	Went along with fate; sometimes I just have bad luck.	0	1	2	3
13	Went on as if nothing had happened.	0	1	2	3
14	I tried to keep my feelings to myself.	0	1	2	3
15	Looked for the silver lining, so to speak; tried to look on the bright side of things.	0	1	2	3
16	Slept more than usual.	0	1	2	3
17	I expressed anger to the person(s) who caused the problem.	0	1	2	3
18	Accepted sympathy and understanding from someone.	0	1	2	3
19	I told myself things that helped me to feel better.	0	1	2	3

0=Not used	**1=Used somewhat**	**2=Quite a bit**	**3=A great deal**		
20	I was inspired to do something creative.	0	1	2	3
21	Tried to forget the whole thing.	0	1	2	3
22	I got professional help	0	1	2	3
23	Changed or grew as a person in a good way.	0	1	2	3
24	I waited to see what would happen before doing anything.	0	1	2	3
25	I apologized or did something to make up.	0	1	2	3
26	I made a plan of action and followed it.	0	1	2	3
27	I accepted the next best thing to what I wanted	0	1	2	3
28	I let my feelings out somehow.	0	1	2	3
29	Realized I brought the problem on myself.	0	1	2	3
30	I came out of the experience better than when I went in.	0	1	2	3
31	Talked to someone who could do something concrete about the problem.	0	1	2	3
32	Got away from it for a while; tried to rest or take a vacation.	0	1	2	3
33	Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc	0	1	2	3
34	Took a big chance or did something very risky	0	1	2	3
35	I tried not to act too hastily or follow my first hunch.	0	1	2	3
36	Found new faith.	0	1	2	3
37	Maintained my pride and kept a stiff upper lip	0	1	2	3
38	Rediscovered what is important in life	0	1	2	3
39	Changed something so things would turn out all right.	0	1	2	3
40	Avoided being with people in general.	0	1	2	3
41	Didn’t let it get to me; refused to think too much about it.	0	1	2	3
42	I asked a relative or friend I respected for advice	0	1	2	3
43	Kept others from knowing how bad things were.	0	1	2	3
44	Made light of the situation; refused to get too serious about it.	0	1	2	3
45	Talked to someone about how I was feeling	0	1	2	3
46	Stood my ground and fought for what I wanted.	0	1	2	3
47	Took it out on other people.	0	1	2	3
48	Drew on my past experiences; I was in a similar situation before.	0	1	2	3

0=Not used	1=Used somewhat	2=Quite a bit	3=A great deal		
49	I knew what had to be done, so I doubled my efforts to make things work.	0	1	2	3
50	Refused to believe that it had happened	0	1	2	3
51	I made a promise to myself that things would be different next time.	0	1	2	3
52	Came up with a couple of different solutions to the problem.	0	1	2	3
53	Accepted it, since nothing could be done	0	1	2	3
54	I tried to keep my feelings from interfering with other things too much.	0	1	2	3
55	Wished that I could change what had happened or how I felt.	0	1	2	3
56	I changed something about myself.	0	1	2	3
57	I daydreamed or imagined a better time or place than the one I was in.	0	1	2	3
58	Wished that the situation would go away or somehow be over with.	0	1	2	3
59	Had fantasies or wishes about how things might turn out.	0	1	2	3
60	I prayed.	0	1	2	3
61	I prepared myself for the worst.	0	1	2	3
62	I went over in my mind what I would say or do.	0	1	2	3
63	I thought about how a person I admire would handle this situation and used that as a model	0	1	2	3
64	I tried to see things from the other person's point of view	0	1	2	3
65	I reminded myself how much worse things could be.	0	1	2	3
66	I jogged or exercised	0	1	2	3

Appendix 5

نموذج موافقة على المشاركة في دراسة

ضغوطات غسيل الكلى وطرق التعامل معها

<u>عنوان الدراسة:</u> فحص ضغوطات غسيل الكلى وطرق التعامل / التكيف ، بين الاردنيين اللذين يعانون من فشل كلوي ويستخدمون جلسات غسيل الكلى .

<u>اهداف الدراسة:</u> 1 - فحص الضغوطات الفسيولوجية والضغوطات النفسية- الاجتماعية الناتجة عن غسيل الكلى عند الاردنين اللذين يعانون من الفشل الكلوي ويستخدمون جلسات غسيل الكلى.

2- فحص العلاقة بين مستوى ضغوطات غسيل الكلى وطرق التعامل / التكيف ، بين الاردنين اللذين يعانون من فشل كلوي ويستخدمون جلسات غسيل الكلى .

<u>ماذا عليّ أن أفعل؟:</u> سيقوم الباحث بعمل مقابلة شخصية مسجلة معي تستغرق حوالي ساعة. ستكون الأسئلة التي سأقوم بالإجابة عليها متعلقة بتجربتي التي أعيشها كمريض يعاني من الفشل الكلوي و يتعالج بجلسات الغسيل.

<u>ضمان السرية:</u> كل المعلومات المقدمة لغرض هذه الدراسة ستعامل بسرية تامة واسمي لن يعرّف به بأي وقت. ولن يطلع على هذه التسجيلات إلا الباحث الرئيسي والمشرف على البحث.

<u>الأخطار:</u> لا توجد أخطار تنتج عن المشاركة في الدراسة ، ربما يحصل بعضالإرهاق الجسدي أوالنفسي عند البعض أثناء المقابلة ويحق لي أن أتوقف إذا شعرت بالإرهاق آو عدم الرغبة بالاستمرار.

<u>منافع البحث:</u> النتائج ربما ستساعد العاملين في المجال الصحي على تفهم أكثر للضغوطات الفسيولوجية والنفسية- الاجتماعية للأفراد اللذين يعانون من الفشل الكلوي وهم على جلسات غسيل الكلى.

<u>الفوائد والحرية الشخصية بالانسحاب من الدراسة</u>: سيكون لي حرية اختيار المكان و الوقت المناسب لعمل المقابلة مع الباحثة .يمكنني الانسحاب في أي وقت من الدراسة بدون أية عواقب. قراري بالمشاركة في الدراسة أو عدمها لن يؤثر على علاج غسيل الكلى المقدم لي في هذا المستشفى.

<u>تصريح بالموافقة:</u> اجابتي في المقابلة المسجلة تعني موافقتي على أن أكون احد المرضى المشاركين في هذا البحث الذي تقوم به إيمان النزلي طالبة الدكتوراه / كلية التمريض/ الجامعة الأردنية.

مع جزيل الشكر على مشاركتكم في الإجابة على استبيانات هذه الدراسة.

<u>عنوان الباحثة:</u> إيمان النزلي/ طالبة دكتوراه / كلية التمريض في الجامعة الأردنية

<u>المشرف:</u> دكتور مؤيد احمد/ كلية التمريض / الجامعة الأردنية هاتف: 5355000 / فرعي 23131

Appendix 6

بحث نوعي

مقابلة مع مرضى غسيل الكلى

1-الأسلة المفتوحة:

- (ممكن تحكيلي بالتفصيل عن معا يشتك مع مرض الفشل الكلوي وغسيل الكلى)

-(ممكن تحكيلي اكثر عن اي ضغوط او صعوبات بتعاني منها بسب مرض الفشل الكلوي وغسيل الكلى).

- (اوصف لي كيف واجهت مرض الفشل الكلوي وكونك تتعالج بغسيل الكلى, كيف تكيفت مع هذا الوضع)

2-أسئلة التعمق:

-هل من الممكن توضيح أكثر لهذه النقطة.

-عندما تقول ....ماذا يعني ذلك.

Appendix 6

Qualitative interview

Open ended questions

Please tell me about your lived experience of being on hemodialysis?

Please tell me about any other restrictions or limitations you face?

Please describe what did you feel is helping you to cope with dialysis?

Please tell me who did you turn to for support?

Probes

Can you tell me more about that?

When you say……………….what does that mean?

الضغوطات وطرق التعامل معها بين المرضى الأردنيين الذين يعانون من الفشل الكلوي وعلى غسيل الكلى

إعداد
إيمان خميس هاشم النزلي

المشرف
الدكتور مؤيد أحمد

المشرف المشارك
الدكتورة كارول ميوسل

ملخص

الهدف

تدمج هذه الدراسة طرائق البحث التي تكشف عن الضغوطات التي يواجهها مرضى غسيل الكلى الأردنيين والإستراتيجيات المستخدمة في التعامل معها واختبار الإرتباطات بين البيانات الديموغرافية مع الضغوطات والإستراتيجيات , كما حاولت الدراسة استكشاف التجربة المعيشة لهؤلاء المرضى .

أهمية الدراسة

مرضى الفشل الكلوي بمراحله الأخيرة داء لا شفاء منه ومهدد للحياة. ويزداد بالأردن عدد مرضى داء الفشل الكلوي الذين يعالجون بغسيل الكلى اللذي يرتبط بعدد من الضغوطات. ومن خلال تحديد تلك الضغوطات وإستراتيجيات التعامل معها ,قد تكتسب الممرضات فهماً واضحاً لهؤلاء المرضى التي من شأنها أن تمكنهم من إنشاء التخطيط الفعّال للرعاية.

منهجية البحث

تمَ اختيار عينة مكونة من مئة و واحد وثلاثين مريض ومريضة من اربع وحدات غسيل كلى في عمان لأهداف الدراسة الكمية. تم قياس الضغوطات المدركة وإسترتيجيات التعامل المستخدمة من قبل المرضى باستخدام مقياس الضغوطات في غسيل الكلى ومقياس إستراتيجية التعامل. و أجاب المشاركون عن استبانة خصائصهم , وتمَ حساب المتوسطات الحسابية والانحرافات المعيارية , كما استخدمت المقاييس المناسبة من الإرتباطات بين المتغيرات. واعتمدت الدراسة التحليل النوعي لبحث التجربة المعيشة لخمس مريضات وأربعةُ مرضى .

النتائج

أظهرت النتائج أن متوسطات الضغوطات النفسية والاجتماعية كانت أعلى (2.56) من تلك الضغوطات الفسيولوجية (2.26), وكان متوسط إستراتيجية إعادة تقيم المواجهة الإيجابية هو الأعلى (1.91) بين إستراتيجيات المواجهة, بينما كانت لإستراتيجية قبول المسؤلية أدنى متوسط. (1.13). وقد أيّدت النتائج تلك المواضيع التي انبثقت عن الدراسة النوعية فمثلا

الوقت الضائع في أيام غسيل الكلى يؤثر على الحياة اليومية للمرضى كما لعبت المعتقدات الروحية دورا رئيساً في العيش مع المرض .

الخلاصة

تشير النتائج إلى أن الضغوطات النفسية والإجتماعية عند مرضى غسيل الكلى عالية وتحتاج إلى الإهتمام من العاملين في المجال الصحي وقد كانت الإستراتيجية الأكثر استخداماً في التعامل مع المرض هي إعادة التقيم الإيجابي التي تشمل الإيمان والصلاة ويمكن للممرضات تخطيط المداخلات التي تقلل من الضغوطات وتساعد هؤلاء المرضى على الاستفادة من إستراتيجيات المواجهة والتكيف المناسبة .

الكلمات الدالة: غسيل الكلى، الضغوطات، طرق التعامل مع المرض.